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ABSTRACT

Eleven papers from a June, 1984, seminar on siblings of mentally retarded and developmentally disabled persons are presented. The following papers are included: "An Adult Sibling Network: A Sharing of Experiences" (B. Cohen); "Siblings as Change Agents for Their Brothers and Sisters: Opportunity or Problem?" (G. Wolpert); "Adult Siblings: The Forgotten Ones Who Got Together to Talk" (R. Medicus); "Siblings as They Appear in Children's Literature" (C. Moore); "Brothers and Sisters of Handicapped Children in Foster Care" (S. Young); "Some Observations Concerning Jewish Siblings" (C. Horowitz); "Life Style Development of Siblings of Special Needs Children: An Adlerian Approach" (B. Fairfield); "Institutionalization of Siblings: What Constitutes Continuing Sibling Responsibility?" (C. Sussman and M. Wolfe); "The Siblings' Perspective: A View of the Handicapped Child in the Family System" (S. Kramer); "The Sibling Child: Identifying and Working with the Siblings of the Family with a Developmentally Disabled Child" (L. Silverstein); "Needed Research Thrusts Concerning and Involving Siblings" (M. Schreiber). The document concludes with reports from three discussion groups: adult siblings, parents, and professionals. (CL)

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PROCEEDINGS

**Second Annual National Seminar
Dealing With**

Siblings of Mentally Retarded and Developmentally Disabled Persons

Theme:

**Siblings, Parents and Professionals
Working Together To Advance Knowledge and Service**

**June 11-12, 1984
Hunter College
of The City University of New York
New York, New York**

Jointly sponsored as a cooperative effort and a community service by:

**Kean College of New Jersey
Social Work Program & Developmental Disabilities Collateral**

**Association for the Help of Retarded Children
New York City Chapter**

**Mental Retardation Institute
Westchester County Medical Center**

**Hunter College
of The City University of New York**

**Edited by
Meyer S. Schreiber, D.S.W.**

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PROGRAM

The Second Annual National Sibling Seminar *Dealing with Siblings of Mentally Retarded and Developmentally Disabled Persons*

Monday and Tuesday, June 11-12, 1984 – from 9 a.m. to 5 p.m.
Hunter College of the City University
68th Street and Lexington Avenue, New York City

■ ■ ■

A Cooperative Effort and Community Service Jointly Sponsored By:

The Association for the Help of Retarded Children, New York City Chapter
Hunter College of the City University of New York
Kean College of New Jersey Social Work Program & Developmental Disabilities Collateral
Mental Retardation Institute (UAF) Westchester County Medical Center, Valhalla, N.Y.

■ ■ ■

Conference Theme:

Siblings, Parents and Professionals Working Together to Advance Knowledge and Service

■ ■ ■

Monday, June 11, 1984

8:45 a.m. Registration; distribution of materials and coffee, tea and danish. Sixth Floor Area, West Building.

9:30 a.m. General Session – Room 615, West Building
Presiding: Gloria Wolinsky

Welcome and Introductions

Donna Shalala, Hunter College
Michael Goldfarb, N.Y.C. Assn. For The Help of Retarded Children
Frank Esposito, Kean College of New Jersey
Helen Murtha, Mental Retardation Institute

Presentation of Awards to Selma G. Miller, Lawrence Goodman and Cory Moore for distinguished contributions relating to Siblings.

Presentation by Blanche Fierstein

A Dramatic Performance: Siblings

Presented by The Kean College Players

■ ■ ■

11 a.m. to
12:30 p.m.

Workshop Series #1

(1) Sibling Perspectives – Room 605

Chairperson: Jack Gorelick

"Being The Younger Sister" – Selma G. Miller

"Siblings As Change Agents For Their Brothers and Sisters: Opportunity or Problem" – Gloria Wolpert

(2) Life Style Development of The Sibling: An Adlerian Approach – Room 603

Chairperson: Jean Bernstein

Presenter: Barbara Fairfield

Seminar Program cont.

- (3) *Two Views of Family Involvement* – Room 609
Chairperson: Brenda Callaway
"The Extended Family and The Sibling" – Esther Ashkenas
"Parent Perspectives: Advocacy and Its Impact Upon Siblings" – Duncan Whiteside,
Mary Kany and Benita Durben
- (4) *Explaining Handicapping Conditions to Younger Children* – Room 610
Chairperson: Harold Michal-Smith
Presenters: Ina White and Mary Bernard
- (5) *Siblings As Guardians for Their Siblings: Some Moral Dilemmas and Problems* – Room 611
Chairperson: Meyer Schreiber
Presenters: Elaine and Lawrence Meyerson

Lunch, Buffet Style

Third Floor Main Dining Room, West Building, from 12:30 to 1:45 p.m.

During lunch there will be meetings for Siblings, Parents and Professionals in their own separate groups to deal with their experiences, needs and suggestions as a basis for formulating strategies for future actions.

Sibling Convenors: Selma G. Miller and Bonnie Cohen

Parent Convenors: Esther Ashkenas and Cory Moore

Professional Convenors: Gloria Wolinsky and Meyer Schreiber



2 to 4 p.m.

Workshops Series #2

- (6) *Genetics: An Area Siblings Need To Consider* – room 605
Chairperson: Adin Merrow
Presenter: Jessica Davis
- (7) *Siblings As They Appear In Children's Literature* – Room 604
Chairperson: Ina White
Presenter: Cory Moore
- (8) *An Adult Sibling Network: A Sharing of Experiences* – Room 609
Chairperson: Jack Gorelick
Presenters: Bonnie Cohen, Lola Simmons, Kathryn Edmundson and Marilyn Jaffe-Rulz
- (9) *Institutionalization and Siblings: What Constitutes Continuing Sibling Responsibility?* – Room 610
Chairperson: Murry Morgenstern
Presenters: Carol Sussman and Mary Wolfe
- (10) *Starting and Stabilizing Community Programs* – Room 611
Chairperson: Carl Smith
"People In Need Services: Services In Need" – Thomas Fish
"Let's Grow Together: A Support and Education Program for Siblings" – Janet C. Weeldreyer



4:15 to 5 p.m. Room 623

Dutch Treat Wine and Cheese Party. Come meet old friends and make new ones.

■ ■ ■

Tuesday, June 12, 1984

9:30 a.m. to
2:00 p.m.

FILM THEATER – a variety of new and innovative presentations dealing with siblings –
Room 615

Chairperson: Terence Gallagher

■ ■ ■

9:30 to
11:45 a.m.

Workshops Series #3

(11) *Another View of the Sibling in the Family System* – Room 604

Chairperson: Marilyn Klein

"The Sibling's Perspective: A View of the Handicapped Child in the Family" –

Sharon Farago

"The Sibling Child: Identifying and Working With Siblings in the Family" – Leonard Silverstein

(12) *The Experiences of Community Child Welfare Agencies* – Room 605

Chairperson: Marjorie Kelly

"Some Observations Concerning Jewish Siblings" – Clara Hurwitz

"Brothers and Sisters of Handicapped Children in Foster Care" – Sharon Young

(13) *Needed Research Thrusts Concerning and Involving Children in Foster Care* –
Room 609

Chairperson: Brenda Callaway

Presenter: Meyer Schreiber

(14) *Work with Groups of Siblings in the Elementary School Setting* – Room 610

Chairperson: Marsha Lupi

Presenter: Marion Klutch

(15) *Adult Siblings: The Forgotten Ones Who Got Together to Talk* – Room 611

Chairperson: Jack Gorelick

Presenter: Rose Medicus

■ ■ ■

Lunch, Buffet Style

From 12 to 1:50 p.m. in the Third Floor Main Dining Room, West Building

Siblings, parents and professionals will continue to meet together to generate an agenda for current and future activity.

■ ■ ■

2 to 4 p.m.

Final General Session – Room 615

Theme: *Setting a Direction for Current and Future Sibling Activity*

Presiding: Meyer Schreiber

Reports from the sibling, parent and professional

General discussion involving all participants to develop directions for current and future activity.

■ ■ ■

Seminar Planning Committee

Lawrence Goodman

Jack Gorelick

Marion Klutch

Marsha Lupi

Harold Michal-Smith

Gloria Wolinsky

Meyer Schreiber, Chairperson

Program Participants

Esther Ashkenas, Parent Advocate, Assn for the Help of Retarded Children

Mary Bernard, Educational Psychologist, Mental Retardation Institute

Jean Bernstein, Super., Social Work Training, Mental Retardation Institute

Brenda Callaway, Asst. Prof., School of Special Education, Kean College of N.J.

Bonnie Cohen, Social Worker, Residential Services, Federation Employment & Guidance Service

Jessica Davis, Dir., Child Development Center & Chief, Div. of Genetics, North Shore University Hospital

Benita Durben, Parent Advocate, Co-Chairman, *On Their Own*

Kathryn L. Edmundson, The Rockefeller Foundation

Frank Esposito, Dean, School of Education, Kean College of N.J.

Barbara Fairfield, Family Counselor, Pediatric Genetics, The John Hopkins School of Medicine

Sharon Farago, Asst. Super. of Curriculum, The Shield Institute

Blanche Fierstein, President, Assn for The Help of Retarded Children

Thomas Fish, Director of Clinical Services, The Nisonger Center, Ohio State Univ.

Terence Gallagher, Asst. Clinic Dir., Assn for The Help of Retarded Children

Michael Goldfarb, Exec. Dir., Assn for The Help of Retarded Children

Lawrence Goodman, Consultant, Mental Retardation Institute

Jack Gorelick, Assoc. Dir., Assn for The Help of Retarded Children

Clara Hurwitz, Dir. of Services to Developmentally Disabled Children, Jewish Child Care Assn

Mary Karry, Parent Advocate, *Community Access*

Kean College Players. Dir.: Peggy Dunn; Gene Foti, Vita Greene, Colleen Murray, Tom Stark and Glenn Wolfson

Marjorie Kelly, Asst. Prof. & Coordinator, Family Studies Collateral, Kean College of N.J.

Marilyn Klein, Dir. Dept. of Communicology, Mental Retardation Institute

Marion Klutch, Assoc. Prof., Coordinator, Graduate Program, Guidance & Counseling, Hunter College

Marsha Lupi, Asst. Prof., Dept. of Special Education, Hunter College

Adin Mellow, Medical Dir., Assn for The Help of Retarded Children

Rose Medicus, Social Worker, Westchester Jewish Community Services

Elaine Meyerson, Prog. Dir., Assn Advancement of The Mentally Handicapped

Lawrence Meyerson, Esq., Gabriel & Ambrosio

Selma G. Miller, Clinical Psychologist, Private Practice

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Cory Moore, Parent Info. & Educ. Coord., Montgomery Co. (Md.) Assn for Retarded Citizens

Helen Murtha, Exec. Dir., W.C.M.C. Mental Retardation Institute

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Janet C. Weeldreyer, Coordinator, Community Resource Services, Western Carolina Center

Ina White, Community Outreach Coord., Institute for Human Services, Kean College of N.J.

Duncan Whiteside, Dir., Resource Center for Developmental Disabilities

Mary Wolfe, Super., Summit Unit, Letchworth Village

Gloria Wolinsky, Chairperson, Dept of Educational Foundations, Hunter College

Gloria Wolpert, Doctoral Candidate, Teacher's College, Columbia Univ.

Sharon Young, Social Worker, Mercy Home for Children

SECOND ANNUAL NATIONAL SEMINAR DEALING WITH
SIBLINGS OF RETARDED AND DEVELOPMENTALLY DISABLED PERSONS

Film Theater

A variety of new and innovative presentations shown from
9:30 A.M. to 2:00 P.M. in room 615.

- 9:30 A.M. SARA HAS DOWN'S SYNDROME - Six year old Sara, who has Down's Syndrome, lives at home with her parents; her three sisters, aged 8, 11 and 18 and her 16 year old brother. She is seen interacting with her family and working in a classroom with other children with special needs. The different members of the family discuss their feelings about Sara and the adjustments they have had to make in their lives. 16 minutes.
- 9:55 A.M. SIBLINGS AS BEHAVIOR MODIFIERS - This film concentrates on the why of sibling involvement. It shows intense closeness of the family with Carrie, a mentally retarded girl. 25 minutes.
- 10:25 A.M. GROUP THERAPY WITH SIBLINGS OF DISABLED CHILDREN - This presentation attempts to describe typical stresses experienced by siblings of disabled children and some of the coping responses they exhibit. 40 minutes. Discussion will follow.
- 12:30 P.M. A SPECIAL LOVE-The story of two siblings told in a warm and sensitive fashion. 20 minutes.
- 1:00 P.M. LET ME TRY: A MENTALLY RETARDED CHILD - The kids have gathered in Martin's backyard to build a treehouse, and Billy has brought along his mentally retarded sister Wendy. When they all go inside to have a snack, Martin's overly protective grandmother insists that it's unsafe for Wendy to play outside with the others. 6 minutes.
- 1:15 - 2:00 Film repeated by request.

CITATION AWARDS

To Selma Miller, Ed. D.

For her strong and effective leadership
in mobilizing siblings as a family resource.

- - -

To Cory Moore

Montgomery County (Md.) Association for Retarded Citizens

For her constant and productive efforts
as a parent in the struggle for recognition
of the concerns of siblings.

- - -

To Lawrence Goodman, M.S.W.

For his pioneering work as a professional
in serving the total family, with special concern
for the needs of siblings.

- - -

Presented At The Second Annual National Sibling Seminar

by

Association for the Help of Retarded Children, N.Y.C. Chapter

Kean College of New Jersey

Mental Retardation Institute, Westchester County Medical Center

Hunter College of the City University of New York

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EDITOR'S INTRODUCTION

In the individual and collective effort to work together to advance knowledge and service relating to siblings of mentally retarded and other developmentally disabled persons, the eleven articles and the reports of the three discussion groups help to further progress in these areas. The variety of settings where this group of siblings, parents and professionals labor, and the concerns and the issues that they confronted, map some of the directions that the increased attention to siblings has accomplished recently.

A number of general observations emerge as one surveys the content of these contributions:

1. The variety of agencies and programs and the approaches taken to serve and to understand siblings helps to advance our current state of knowledge and the provision of services to those siblings who desire or need them.
2. The amount of material flowing from siblings themselves, or utilizing the sibling experience, is limited. A beginning has been made to bring into being the perspectives and psychosocial worlds of the sibling.
3. The research emphasis is not a major area of interest yet; most of the materials deal with practice efforts, with service delivery.
4. Theory building is indicated in one article, and interestingly enough examines how the insights of Adler reveal new understandings of the sibling of a retarded or other developmentally disabled person.

The individual presentations yield a variety of important and interesting experiences that contribute to the building blocks of our knowledge base about siblings.

Cohen sensitively depicts in her short article how an adult sibling network facilitated a sharing of experiences for her. She shares with us some of the struggles, pain, growth and freedom she experienced and is dealing with as she receives support and validation from her peers. She throws a needed spotlight upon the sibling experience.

Wolpert raises some interesting and troubling questions about how siblings relate to each other, and what the boundaries of relationships are and how roles might change. She discusses the use of the sibling as a therapist with the brother and sister and helps us look at the issues involved.

In her article on adult siblings, Medicus charts the paths a community agency has taken to respond to a felt need in the community. Her account of the approach she takes as a sensitive worker and her case materials adds considerably to Cohen's previous insights as a sibling.

Children's literature and the world of fiction are used by Moore in her examination of the small but increasing literature dealing with siblings to help us understand how the general culture has advanced in its understanding of the sibling's situation.

Two articles from the field of child welfare take different paths in dealing with siblings. Horowitz postulates that there are some common features regarding loss in being a sibling of a person with a handicapping condition or a Holocaust survivor. Young deals with how last year's conference helped to stimulate and shape the development of a service to the siblings of the children in foster care placement.

The work of Adler to understand the life style development of the sibling of the special needs child is developed by Fairfield. As Adler was one of the few theorists to refer to siblings, this material takes on significant meaning for all of us. The use of case illustration would have added considerably to the value of this short article.

Wolfe and Sussman take us into the setting of the institution and discuss how they attempt to involve adult siblings in relating to their aging brothers and sisters.

The siblings' perspective is presented by Kramer through the development of a formal research study using the theoretical underpinnings of R.F. Bales. Four major questions are raised and dealt in a systematic fashion.

Work in a cerebral palsy center provides some experiences from Silverstein who focuses upon management concern in the family. He deals with the effect of family organization upon the 'management' of the sibling.

Finally, Schreiber looks at the directions research regarding siblings has taken, and suggests some further needed areas of research development.

Collectively the eleven articles move our knowledge and service approaches forward. The materials do reflect some problems, such as the lack of familiarity with the literature on the part of some contributors and hence the limited knowledge building. But nevertheless the work described in these pages attests to the interest of a small but increasing group of siblings, parents and professionals to know and to do more.

The Mental Retardation Institute of the Westchester County Medical Center through its director, Helen Murtha, was very helpful in making possible the development of the proceedings of The Second National Seminar.

Dr. Jack Gorelick, of The N.Y.C. Association for The Help of Retarded Children, also earns our gratitude and thanks for his constant interest and his faith in the individual and collective activities of siblings, parents and professionals.

Meyer S. Schreiber, DSW, Editor
Kean College of New Jersey

AN ADULT SIBLING NETWORK: A SHARING OF EXPERIENCES

- Bonnie Cohen

It isn't easy to talk about being a sibling. However, the encouragement and support of the sibling group has allowed me to be more comfortable.

I am 28 and single. I co-manage a residence for retarded adults and I am working on a Master's degree in social work. I chose this line of work because I had on-the-job training! I felt a need to contribute to a system of support on which I and my family had been dependent. My brother is 31 and mildly retarded. Although he has made a lot of progress in 31 years, he is still retarded and most likely will always be disabled. There will always be obstacles which will confront him. What has and will change, are my attitudes and feelings. I had always believed that my brother's disability marked me as different. Through my work, therapy and support group, I have a new, healthier prospective about myself, my brother and my family.

We are a normal family in many ways. I am a normal part of my family and I deserve a normal life. We all do. We are unique in certain ways because of Allen and the way we face his problems, accomplishments and needs.

I am pulled in the direction of my brother's handicap. We all are. It is o.k. to pull away from the handicap, as long and as hard as is necessary to achieve an identity of one's own.

I felt deprived of many things which are the norm for most children. A normal family life was something I had many fantasies about. It is only now that I can and do acknowledge those feelings. In the past, I felt too guilty.

All young adults struggle for their own identity. For siblings, there are additional tasks and issues. Let me enumerate:

1. We must separate ourselves from the stigma we grew up sharing with our families.
2. We must value our own accomplishments and learn how to achieve. Often we feel guilty about any recognition of our own accomplishments. All too often the focus of our families is on the disabled, not the "abled".

It is extremely important for siblings to meet these tasks successfully, so that we are prepared for the future, adult concerns which will be ours until we die:

1. Our choice of mates includes concerns about their acceptance of our siblings.
2. Our family genetics may affect our own children, how can we be sure?
3. What responsibilities will be passed on to us by our parents? We have questions about whether we must accept them, must we be always prepared to? Can we accept all the decisions which our parents made, how should we make decisions which they have left unmade?

Unfortunately, many siblings are expected to take responsibility, but have not been given any opportunity to participate in the family choices.

As a result of my professional work, I was able to earn the right to share decision making and encourage risk taking. This was balanced against my parents' need to be protective. In being part of the decision making, I bought a lot of responsibility for those decisions.

I feel that this prepared me for the future which we all fear in some ways. I know I can manage the responsibility without becoming disabled myself.

Something special occurred a few weeks ago. My family went away for a holiday to celebrate my mother's 60th birthday. Although my brother's disability was evidenced many times, it was not the focus of our attention. We succeeded in having fun in a very unique way for us--as a normal family.

SIBLINGS AS CHANGE AGENTS FOR THEIR BROTHERS AND SISTERS:
OPPORTUNITY OR PROBLEM?

- Gloria Wolpert

The topic I will address in this paper is Sibling Involvement in the Education of Handicapped Children. This is a growing trend in the literature and school systems. I would like to start off with a brief discussion of the history, move on to research findings and implications, and conclude with the moral issue questioning whether it is or is not a good idea to give the non-handicapped sibling the skills and responsibility for helping to educate the handicapped brother or sister.

The history of sibling involvement in education parallels the sequence of parent involvement, but at a later date of 12 to 15 years. In the 1950's, when the parent movement originated and flourished, there was no consideration for including the non-handicapped siblings. In the 1960's, siblings were regarded as needing helping services and benefitting from therapy due to family life cycle problems associated with having a handicapped family member (ie. stagnation of caretaking family roles, and stress caused by the switch of birth order position with younger non-handicapped siblings). Thus social workers and psychologists were the first people to become interested in siblings of handicapped children, and educators were to follow later. By the late 1960's and 1970's, siblings were often educated with parents in order to maintain consistency in home programming for the handicapped. Finally in the late 1970's and 1980's the literature documents the sole use of the sibling, as a: "therapist", "behavior modifier", "tutor", and "behavior change agent".

There are two research implications pushing for increased sibling involvement. The first is successful reports of peer tutoring in the schools. The use of school peers to help the educational process was found to be more motivating to problem students, and both parties (the student and tutor) have demonstrated meaningful learning as a result of such experiences. The theory originating from this movement is that if peers were found to be successful, siblings should be even more so, because they have the advantage of being familiar with customary patterns of the home, share the commonality of the same parents, are non-voluntary members of the home, and share lifelong, caring relationships with the handicapped student.

The second research implication comes from behavioral psychologists. They found that behavior modification principles can be learned and carried out by any trained individuals, not only those professionals in the fields of psychology and education. I feel that these two forces have

intermeshed, and as a result have promoted the push for increased sibling involvement with their handicapped brothers and sisters.

The next question becomes: How do we involve the sibling? The research cites two alternatives. The first is a "total family" approach, which began when psychologists went into the home to study why their behavioral home programs were not successful (Miller and Miller, 1976; Miller and Cantwell, 1976). They found that siblings were inadvertently disrupting skillful parent attempts to decrease inappropriate behavior (such as compliance and verbal communication). In these instances when the siblings were included in the parent training sessions, the handicapped child's maladaptive behavior decreased dramatically. Cash and Evans (1975) have also done a study utilizing this approach, and trained preschool siblings to behaviorally work on one task with their handicapped brother or sister. The preschoolers learned the techniques by watching videotapes demonstrating behavior modification interactions, and parents were used as observers in order to monitor the home program. This program model worked very successfully, and illustrated the need for monitoring sibling behavior.

The next alternative approach to involving the sibling is to use the sibling only in training the handicapped child. Cicirelli (1976) did a study on non-handicapped children, and used sibling dyad teaching pairs (older vs. younger, brother vs. sister). He found that the most efficient dyad pair was when sibling ages were at least four years apart. The best teaching pairs usually had an older sister, which was explained as a consequence of the older sister modeling didactic teaching techniques from both her mother and (predominantly female) teachers.

Weinrott (1974) ran a six week Sibling Training Program for ages 10-18 years during the summer at Camp Freedom. Non-handicapped siblings would observe behavior modification techniques, undergo guided instruction, and then interact with their handicapped sibling. The program demonstrated encouraging results but limited documented success, possibly due to the erroneous expectation that a short time span of six weeks could modify years of behavioral patterning between siblings.

Schreibman's more recent "teaching" study (1983) using three sibling pairs, all of which contained an older, non-handicapped sibling who was trained by videotape, has come up with two important results. The first is that the non-handicapped siblings showed a generalization of trained skills in other ways, on other tasks, and in other situations. These same siblings also showed improved attitudes toward the handicapped child, as reported by parents from their conversations with the siblings. The trained sibling showed a shift in perspective from focusing on what the handicapped child

could not do and misbehavior, to focusing on the small rewarding successes that the handicapped child was able to accomplish. All of these studies point to the possibility that having siblings tutor or train the handicapped child may be beneficial to both parties.

Unfortunately, one must keep in mind the problems with the research methodology of these studies, and be wary of specifying causative results. Most of the research involved case-studies, which, being running logs of occurrences and consequences, make it extremely difficult to pinpoint causes of behavioral change. Also, small numbers of subjects were used (except for Circirelli's study), which makes it difficult to generalize the results to other situations. There were no control or comparison groups used which creates the large internal validity problem of possible outside causes influencing results, for example other events (history), or the maturation of the child. Finally, there is little measurable data on the performance improvement of the handicapped individual, a surprising fact when one considers that this was the main idea of involving the siblings in the first place! Thus, much more research needs to be done in this area before causative relationships can be determined.

This brings me to the moral issue: Should siblings be involved in educating handicapped brothers and sisters? Or is this getting educators into the dangerous area of making siblings their brother's keepers and changing family roles and creating a "therapeutic family" (Schreiber, 1983). The literature documents both pros and cons to this issue. It has been demonstrated that it is often more motivating to learn from someone closer in age. Siblings themselves can learn through the process of teaching their handicapped brother and/or sister. The sibling family role is one of consistency and life-long influence. The literature also implies that one can expect an increased number of positive interactions and attitudes when siblings become involved in education. However, using the sibling has often created uncomfortable family situations, where parents in particular fear "shared secrets". Professionals have also noted attention span and follow through problems, where young children especially will tend to lose interest after some time, and become sloppy with application of the techniques.

This issue of whether or not it is beneficial to involve siblings in educating handicapped children has not yet been resolved, and probably won't be for some time. More longitudinal studies in this area are definitely needed. Perhaps it will only become a viable alternative depending on the family situation and interest of the sibling. It is my hope that educators will opt to offer the siblings the techniques and skills needed to educate the handicapped person, and let each sibling make his or her own individual and situational choice.

References

- Cash, W.M., and Evans, I.M. (1975). Training preschool children to modify their retarded siblings' behavior. Journal of Behavior Therapy and Experimental Psychiatry, 6, 13-16.
- Cicirelli, V.G. (1976). Siblings teaching siblings. In Allen, V.L. (Ed.), Educational Psychology, N.Y., N.Y.: Academic Press.
- Miller, N.B., and Caltwell, D.P. (1976). Siblings as theapists: A behavioral approach. American Journal of Psychiatry, 133(4), 447-450.
- Miller, N.B., and Miller, W.H. (1976). Siblings as behavior change agents. In Krumboltz, J.D. and Toresen, L.E. (Eds.), Counseling Methods, N.Y., N.Y.: Holt, Rhinehart and Winston.
- Schreiber, Meyer, Interview, New York, NY Sept 1983.
- Schreibman, L., O'Neill, R.E., & Koegel, R.C. (1983). Behavioral training for siblings of autistic children. Journal of Applied Behavioral Analysis, 16(2), 125-138.
- Weinrott, M.A., (1974). A training program in behavior modification for siblings of the retarded. American Journal of Orthopyschiatry, 44, 362-375.

ADULT SIBLINGS - THE FORGOTTEN ONES

- Rose D. Medicus

About ten years ago, while my former agency was having the building painted, I observed that one of the painters was lingering outside my office door. He appeared tense and I asked if anything was bothering him. He fumbled momentarily and then blurted out the question "Is retardation contagious? If it is, I have children at home and I don't need this job that badly."

This encounter was only a decade ago. If this was still one of the prevailing impressions about retardation, is it any wonder that parents have continued to suffer at the attitudes expressed about their handicapped children? It was certainly understandable that they withdrew and became overprotective of the disabled child while they tried to battle internally the shame, the guilt, the anger, depression and disappointment. Subsequently, many normal siblings became the "deprived" children as the families struggled to meet the demands placed on them - emotionally, medically and financially.

My training and experience have covered the gamut of services from the counseling of parents in pre-school groups to working with the adult retarded person in day treatment, sheltered workshops, recreational and residential programs. I have witnessed and participated in the existing development of varied programs for developmentally disabled persons.

Currently I am involved with such adult retarded individuals and their families. I am involved in a special project that has been funded through a grant from the New York State Developmental Disabilities Planning Council.

Although my agency, Westchester Jewish Community Services, is part of the New York Federation of Jewish Philanthropies, its services are non-sectarian. The agency has a strong commitment to respond to social service needs as they arise in the community.

In the last ten years the agency administration and staff became increasingly involved with families who had adult handicapped relatives living at home. Concern was mounting for these families who needed residential placement for their children and/or siblings.

Westchester Jewish Community Services responded to this growing need by opening five ICF community residences serving 52 clients ranging in age from the early 20's to the age of 82. The range of disabilities varied from mildly retarded, dual diagnosed to the profoundly retarded, multiply handicapped

non-ambulatory client. Except for one house, the great percentage of the clients are re-settled clients under the terms of the Willowbrook decree.

Placement in a group residence raised all kinds of issues again that had surfaced at the milestone in the clients' lives - anxiety, fear, guilt, etc. WJCS had insisted on group participation by families in the one house that was primarily community based as part of the placement procedure. This seemed to be helpful to all the placement process.

Because community residential placement brought about a re-definition of family roles, clinicians hypothesized that families could use supportive services of a self help group. Clinicians also thought that more active participation in house activities through a family volunteer corps might prove effective in working through many of the emotional issues: WJCS received a grant to implement such a program if the concept was viable.

A needs assessment was undertaken by an agency psychologist, a graduate research student and the project coordinator. An anonymous attitudinal questionnaire was developed and distributed to 90 full time direct care and clinical staff to determine whether staff would accept additional family involvement. The overwhelming response (86 replied) was that families could not be counted on as regular volunteers; however, relatives would be welcome to participate to a greater extent in special functions and holiday events which are times of greater stress for clients and families.

Concomitantly with the staff questionnaire the agency psychologist and research student developed an attitudinal questionnaire for family members. Anonymous questionnaires were mailed to 80 relatives. Forty-six questionnaires were returned. Of these twenty were completed by siblings varying in age from 20 to 76. In questions relating to additional involvement in an ongoing volunteer program, there was a resounding "no interest". Eight siblings showed some interest in further participation in holiday events.

There was a section on the questionnaire which left space for the relative to ask what services would be most beneficial to you now. Parents and siblings responded by requesting educational and informational material in the following areas:

1. Role and responsibility of siblings
2. Guardianship
3. Problems of aging and chronic illness of the handicapped individual with implications for the client and his/her family.
4. Living with guilt

It was fascinating that the replies indicated concrete informational issues but each of the subjects is emotionally charged. The responses were interpreted as meaning that the family members do not wish a long term commitment to or in "therapy" groups.

The agency is going to respond to the families requests by offering a mini-series in autumn 1984. These lectures and discussions may lead to other developments in programming by WJCS.

As the plans for the series have been developing, I have been interviewing a number of siblings. Some of these are siblings of the clients, others are staff members and others are siblings of the disabled seeking residential placement.

The prime sentiment that prevails in all of the interviews is "too little, too late." The siblings all have said "we are too old, too burned out." "We have made our own kind of inner peace with our situations." Other typical comments are "don't rock the boat," "don't upset the family anymore." Comments like these are familiar to all people who have worked with the developmentally disabled.

A few examples of interviews with siblings will help illustrate the point as part of getting acquainted with the families of the residents. I attended a party, introduced myself to Mr. C, the brother of Mark. My introduction was hardly out of my mouth when Mr. C. made some of the following statements:

"My brother was the baby of four boys. Everything was done for him not us. My mother died too young. She gave her life to Mark and we had to be content with what was left over. My mother was a kind, loving woman who had suffered so much pain and shame that she became too overprotective of Mark. No one was allowed to criticize Mark in our house.

Because of community and other family members rejection, Mother more and more kept Mark a baby. He was not allowed to develop the skills he could have. My brothers and I found it hard to understand why our family was the only one singled out to have a retarded brother."

There was the promise to always look after Mark. It was only after the mother's death and father's illness that Mark was placed in a stable institution. By then all of the brothers were in their thirties.

Mr. C. is grateful that his brother has been relocated in a lovely residence near his own. This is particularly true now that his older brothers have retired because of illness and moved away from the area. Mr. C. remains the sole

family contact. Involvement is easier but he made it clear that he wants no further demands placed on him.

We discussed why he is still involved. Rather sadly he stated "Mark is my brother and I do love him and care about him. I also am committed to my promise to my parents that I will see that he is cared for properly."

The ambivalence as he spoke was loud and clear. It did not require a professional to see that at age 60 plus, Mr. C. still feels his own deprivation and shows his pain and resentment.

An interesting comment made by the Program Director of the house is that at a quarterly conference for the ISP, a negative behavior of Mark's was discussed with some planning on how to modify the behavior. Despite reassurances that the behavior was not serious and did not affect Mark's status in the house, Mr. C. was overheard telling Mark that he would no longer visit if the behavior continued. Accordingly, sessions then took place with Mr. C. when he shared his fears that Mark might jeopardize his status in the home. Mr. C. was overly fearful that the total care of Mark might fall on him again and it was too heavy a burden to bear.

Another interview proved most enlightening to me. I visited the various group homes to share the results of the questionnaire with staff. At one of the homes, Amy, one of the counselor/trainers called me aside and asked to speak with me privately.

Amy felt the agency was providing valuable services for families of the residents; however, she commented the "families who place their relatives have it all. It's someone like myself and my sisters who are the forgotten ones." The counselor explained that some service had been offered her parents that had not been fully utilized in helping her brother Roy, age 30, and moderately retarded. Amy was one of four sisters and made it clear that her sister and she felt much less important and much less loved than the only son.

Amy and her sister seem to be more sensitive to the parents' and brother's needs. Both have chosen the helping professions and feel they can do a better job because of their experience and sensitivity.

Recently the parents retired and moved to Florida with Roy. They have decided to will their house locally to Amy and her sister with the provision that they take care of Roy for his lifetime.

When I inquired about the meaning of this demand on her, Amy replied that her sister and she will honor their parents' request. However, Amy feels that is her parents had been able

to accept counseling offered to them by workshop staff years ago, Roy would have been living in a community residence with a much fuller life than he currently enjoys. He could function on a higher level. Amy is concerned that life will be tough for all when her parents die. Her sister and she will be more demanding of Roy. She is also concerned that if she wishes to marry, would a husband share her with Roy? She said her own guilt would not allow her to let her brother down if he was in need. Because of this dilemma, she feels that this stress will be lifelong for her.

When asked about suggestions as to how parents can help normal siblings, Amy recommended that families seek and use any help offered through community education sources when the child is young. She asserts: Urge families to involve the siblings from the beginning as part of the whole plan for the handicapped child. Being a part of the planning would make the other children feel important, too, she adds.

The other point Amy stressed was the need for the Church to become more knowledgeable in helping all of the family members. In her case this was important since religion was a major strength in her parents. Amy's final statement to me was pathetic, with tears she said "if you don't start young, it's too late."

Another sibling situation came to my attention within the last two months. Rachel, age 28, is being married this month. To date, she has lived at home with her parents, a sister who recently married and moved to Florida, and two brothers, age 25 and 35, who have cerebral palsy, are retarded, and are both wheelchair bound.

The older brother was withdrawn from a program because of the disagreement between the mother and staff at the program. This brother is difficult to handle. A homemaker comes 4 hours a day to help bathe the brother and work with him on activities for coordination. The younger brother attends a program but dislikes it also. There is a great deal of antagonism between the two vying for attention.

Rachel has helped the mother with the care of the brothers as much as possible. Now that she will be leaving home she is concerned that her mother is having problems with arthritis and will be unable to handle the brothers by herself. Rachel was rather evasive in discussing the father's role saying that he helped with marketing, etc.

WJCS had been contacted by Rachel as a potential residential placement for the brothers. Rachel had called without notifying her parents because she felt guilty about leaving and showed genuine concern for her mother's and brother's future.

We talked about the placement process and the need for parental involvement. We spoke at great length about her needs as well. According to Rachel, her sisters and she accepted this way of life as being "normal." Her sister and she always had been involved in the care of the siblings. She denied any anger at being deprived of a normal childhood - the family never went anywhere together or had a vacation because of the difficulty in transporting two non-ambulatory family members.

Rachel said there had never been any discussion of feelings with the parents over having two handicapped children in the family. Neighbors and family had always been supportive.

Reluctantly, the mother came in with Rachel at a later date to talk about placement. The husband did not come in although the homemaker was in the house at that time.

Mrs. Z. appeared outwardly to have coped well with a most difficult life. She did express anger that her husband's job had been phased out which meant additional hardship. They had been forced to sell their home and were moving within weeks to a smaller, less costly house in a less expensive area. This move meant the two handicapped sons would be forced to share a room and would increase the existing tension between them.

I admired her stamina as she described her routine. We talked about placement which seemed to be something that would be necessary in time. Mrs. Z. denied being overwhelmed. She was a proud woman and wished to appear strong. She insisted that God gave her the strength to cope. She said that's the way she has lived and will continue to live only one day at a time. The homemaker from the agency had confirmed that there was a horrible marital situation that was being ignored. Mrs. Z. "lost" herself with the boys and did not have to deal openly with the marital relationship. Mother was "everything" to the whole family and the father was left on the sidelines.

I attempted to help Mrs. Z. with some practical suggestions when she moved. I doubt if she will use the help. The mother was so well defended and has functioned up to now with the strength drawn from her religious conviction. It would be devastating to her at this point to tamper with those defenses. She was made aware that services would be available if she wished to avail herself.

In several conversations, thereafter, with Rachel, she kept saying that placement would be the greatest gift that could be offered to the whole family. I asked Rachel if a sibling group was available would it be helpful. She wasn't sure because she is an introvert and finds it difficult to share her feelings. She wishes that something might have been available when she was younger. She thinks it may be too late for her.

With Rachel moving away, I made suggestions about genetic counseling and counseling that might be important for her marital relationship. Her family life had more drama than a soap opera but as I observed the tragedy of the mother and daughter. It was the young woman who reached me emotionally. She truly had been the "forgotten one" in the life of the family.

These cases have pointed out a number of issues that we as professionals need to be aware of when we work with the siblings of the retarded. This is especially true in working with the adult siblings:

1. Retardation is a family affair. The pain, the anguish, the shame and the guilt of having a handicapped child and/or sibling should be shared from infancy.
2. Be aware that there is frequently a double standard for child rearing. The normal siblings often are asked to forgo a normal childhood. Milestones such as graduation, family outings, etc. are not attended or given much attention because the parental involvement with the handicapped youngster has drained the parents' energy. The normal sibling feels rejected and angry at the loss of equal parental attention.
3. Services for the families have been too few, too late. All siblings responded with enthusiasm at the suggestion of sibling groups at an early age.
4. Better education of the public is necessary. The community at large needs to be more sensitive to the problems of families with developmentally disabled children.
5. There should be better education and orientation of staff dealing with parents and the siblings of the developmentally disabled. Staff needs to understand the pain, the frustration and the ongoing need to hope that families require to function.
6. It is essential that siblings be involved in long range planning for the disabled family member. The involvement should be in all areas - schooling, workshop, community residences, etc.
7. Parents need to know more about guardianship and/or other types of financial planning for the disabled child. Siblings want to take part in this area of planning, too.

8. Genetic counseling should be made more readily available to siblings to quell fears and help siblings approach realistically their prospects as future parents.
9. The greatest need expressed by all siblings is their need not to feel guilty at having lives of their own. Siblings don't want to be held emotional prisoners by promises to dying parents made under stress that will be difficult to fulfill.

There have been tremendous inroads in the field of retardation during the last decade. The government now is trying to rally around family support systems as my grant attests. Our agency will continue to offer emotional support and concrete service to those who request it; however, the thrust must continue to be towards the family from the time of birth of a handicapped child. Only then will the normal siblings no longer be the "forgotten ones."

SIBLINGS AS THEY APPEAR IN CHILDREN'S LITERATURE

- Cory Moore

This workshop is different from most. It relies on fiction, not fact. It will not call for much sharing. I hope you will find it fun; I loved preparing for it.

Let me, right up front, start off with a couple of disclaimers. I am not a sibling, at least not of someone with a handicapping condition; I am rather the parent of Leslie Ellen - a daughter with multiple handicaps, both physical and mental. I am the mother, also, of the two very special and wonderful people who framed her growing up years - her older sister, Laurie, and her younger brother, Kenny. I know the world of the sibling through observing, through reading, through listening, through guessing. It may be, it probably is, that most books for children seen from the sibling perspective have been written by parents, teachers, professionals, interested observers, rather than by sibs. In that sense, what rings true for me may not ring true for you who have lived and are living the very special role of brother or sister. I offer you my observations gleaned through a wealth of reading. I have chosen the books I'll review today because in almost all cases they touched me, and I find them to one degree or another real, compelling, honest.

Once upon a time, when you all were young enough, you probably asked the older ones to tell you a story. I will share with you today as many stories as time will permit, often in the words of the author to give you the real flavor. You can't imagine how delightful it is to have a captive audience! I hope the immersion will not be too overwhelming and that you will someday soon seek out the stories you don't already know for yourselves; they make good reading. Because I had the luxury of developing my own list, it is extensive but not all-inclusive.

The books are all listed and annotated on the handout. They are all books for children or young adolescents. They are all told from the sibling point of view--either directly, in first person, or by the author who writes from the perspective of one sibling in a family that contains a person with a handicapping condition.

Siblings in books are used in many ways: to further the story line, to share information about the disability, to provide someone with whom the young reader can identify. Now certainly, other characters could be used to further these aims as well. How is the fictional sibling fleshed out so that his or her most special role becomes clear and real? Does the unique world that an actual sibling of a person with a

developmental disability inhabits get portrayed? In many instances in the children's literature I will describe to you, I would submit, "Yes." Insofar as good literature can put the reader into the shoes, the mind and the heart of another, several authors have succeeded admirably.

Let me paint some common themes, strands that run through the experiences of these very real, yet unreal children.

Siblings, by and large, tend to be sympathetic characters and not unrealistic in their appraisal of how their brother or sister affects them and their lives and the lives of the rest of their family. In more than one instance in the books I'll be talking about today, the struggles of the family results in the separation of the parents. In more than one instance, the disability of one child necessitates a family move over the protests of other children.

Siblings search for explanations. The brother in DON'T TAKE TEDDY decides that a mind is like a machine and his brother's mind is missing a thinking part; Byar's heroine sees life as a set of stairs and for her brother Charlie the steps are small and difficult; Lydia in ME TOO imagines her sister's mind "to be laid out in thin little strips no wider than a woman's little finger and smooth -- no kinks in them or bulges. Lornie did not experience things, not so you could notice it. She only observed."

Several siblings, some older, some younger than their brother or sister with a disability, feel tremendous responsibility for the care of the sibling. In some cases, the parents request the help; in some the child recognizes the exhaustion and need of his or her parent. In one case, responsibility is even imagined for the handicapping condition itself (Spence). In another, the sibling assumes the enormous responsibility of "saving" his brother from an imagined criminal confinement (Friis-Baastad). Further, siblings frequently assume the beyond-their-years role of teacher, or surrogate parent, of model, of protector--the only one who really understands.

In every account, the sibling with the disability causes embarrassment, concern, and a recognition that a close family member is outside the mainstream and that, because of being related, the family carries its own specialness which may get in the way of friendships with peers and being accepted for oneself. Often siblings protect their parents from their feelings; they understand, as Helen Featherstone puts it, how "touched and how wounded" we can be. And so, often, siblings are left alone with confusion and with little support.

As in real life, fictional siblings feel the effects of the double standard. Parents seem to delight beyond measure in the

smallest of their handicapped child's accomplishments and yet seem disinterested, or at best accepting as a matter of course, the triumphs, often significant, of the nonhandicapped child. "Unfair" is a word often used or thought in the literature.

There is, in the most penetrating of the accounts, a coming to terms that there is usually no easy solution; that what may work for one family or one family member is not what will work for another, that we all--parents and siblings--collectively and individually must arrive at our own understanding and our own way of coping.

And yet, and yet...There is, along with all the difficulties and negatives, side by side with the ambivalence, there is caring, a wish to understand, love. There is, in almost every account in the children's literature I've read, a growing up in emotional awareness, a thoughtfulness about the sibling, a perception that by virtue of their relationship with their sibling, our young heroes and heroines may have even greater knowledge of those aspects of life that go beyond the superficial than the adults--teachers, neighbors, sometimes even parents--with whom they associate. It is not always a comfortable knowledge; it does, however, reassure the reader that difficulty, trauma, adversity--in this case the problems associated with a family role--can create its own special brand of courage.

* * * *

The books I have found written from the special perspective of a sibling are about four disabilities: learning disability, hearing impairment, autism, and mental retardation. I'm prepared to share them all with you in detail but to drown you in make-believe siblings is not, presumably, the intent of the conference. I will therefore, and reluctantly, be selective in my sharing.

One would expect books for the very young to minimize the difficulties of the sibling while being reasonably accurate about the problems of the handicapping condition itself. I would, incidentally, particularly commend Peterson's *I HAVE A SISTER, MY SISTER IS DEAF*, for its gentle understanding. Now when the handicapping condition is mental retardation, our fictional siblings do not minimize. The words may be easy reading; the ideas they express are not.

The books shared and read from are listed. See the addended handout: *THE SIBLING PERSPECTIVE, BOOKS FOR CHILDREN ABOUT CHILDREN WITH HANDICAPS: FROM A SIBLINGS'S POINT OF VIEW* for annotations.

MY SISTER IS DIFFERENT by Betty Ren Wright.

MY SISTER by Karen Hirsch.

A SPECIAL KIND OF SISTER by Lucia B. Smith.

MY BROTHER STEVEN IS RETARDED by Harriet Langsam Sobol.

In the preceding four books for the youngest audience are almost all the themes, the common threads. Even the lost child, a favorite device, appears. Families in these primary books are still together and parents are by and large understanding and supportive. The dark feelings are there and the speculations and anger and wonder and ambivalence.

Let's move on to more complex tales.

In both books on your list involving autism, the setting is far away. THE DEVIL HOLE takes place in an Australian seaside town. At the start of the story, Kenneth is 12, Douglas 10, Adrienne 7. Douglas is missing in a fog the night before Mother leaves for the hospital to give birth to Carl. Douglas is a sensitive and imaginative youngster with a special caring for the new baby. "He stopped crying when Douglas took him," Adrienne told her mother in wonder. Sometimes the caring seems one-sided.

Three more of my favorites are ME TOO by Vera and Bill Cleaver with Lydia, one of the most delightful of heroines and authors who do not compromise with truth, WELCOME HOME JELLYBEAN by Marlene Fanta Shyer and WHAT ABOUT ME? by Colby F. Rodowski. In the last selection, we plunge right into this story of ambivalence, demands, needs, hate and love. The negatives are as clear as any writing can be. The narrator is 15 year old Dorrie; her brother, "Fredlet," is 11. The book ends with Fred's death.

So even in death, there is some ambivalence. And maybe also parents who do understand sometimes a lot more than siblings realize, or maybe they don't. We rarely know another's truth. All we can do is try to understand, to connect. That is the value of creative children's literature.

THE SIBLING PERSPECTIVE

BOOKS FOR CHILDREN ABOUT CHILDREN WITH HANDICAPS: FROM A SIBLING'S POINT OF VIEW

Learning Disability

Lasker, Joe. HE'S MY BROTHER. Albert Whitman, 1974. 36 pp. (Ages 3-8)

An older brother talks realistically, yet sympathetically, about Jamie, a boy whose physical and mental development are uneven--a boy with "the invisible handicap."

Hearing Impairment

Arthur, Catherine. MY SISTER'S SILENT WORLD. Children's Press, 1979. 30 pp. (Ages 5-9)

Heather celebrates her eighth birthday in words and photographs. Her older sister describes what a world without sound must be like.

Peterson, Jeanne Whitehouse. I HAVE A SISTER, MY SISTER IS DEAF. Harper & Row, 1977. Unpaginated. (Ages 5-9)

A young girl describes what her little sister who is deaf can and cannot do in this gentle, feeling story.

Autism

Parker, Richard. HE IS YOUR BROTHER. Brockhampton Press, 1974. 88 pp. (Ages 9-12)

By way of a series of believable incidents, the family of a young autistic child with a helpful older brother learns to "get through" to him.

Spence, Eleanor. THE DEVIL HOLE. Lothrop, Lee & Shepard, 1977. 215 pp. (Ages 12-15)

This engaging novel of an Australian family spans the four year period beginning shortly before the birth of Carl who is autistic. Carl's different behavior, the reactions of observers, and the consequent disruptive effect and emotional problem for parents and siblings are skillfully and perceptively presented.

Mental Retardation

Baldwin, Anne Norris. A LITTLE TIME. Viking Press, 1978.
96 pp. (Ages 8-12)

From the point of view of 10-year-old Sara, life in a family which includes a four-year-old brother with Down's syndrome is described. The reactions of others, the long-term issues, as well as the daily problems and rewards of living with a child who is retarded, are simply and honestly presented.

Byars, Betsy. THE SUMMER OF THE SWANS. Avon Books, 1974.
(Ages 9-14)

This is the sensitive story of 14-year-old Sara and the summer night when Charlie, her mentally retarded brother, disappears. It won the Newberry Medal.

Cleaver, Vera & Bill. ME TOO. J.B. Lippincott, 1973.
158 pp. (Ages 11-14)

Twelve-year-old Lydia and Lornie are identical twins with one important difference--Lornie is retarded. The Cleavers write with imagination, insight, and daring.

Friis-Baastad, Babbis. DON'T TAKE TEDDY. (Translated from the Norwegian) Charles Scribner's Sons, 1967. 218 pp.
(Ages 11-14)

A 13-year-old boy tries to save his older brother who is retarded from possible imprisonment; their escape is an arduous adventure.

Hamilton, Virginia. SWEET WHISPERS, BROTHER RUSH. Philomel Books, 1982. 215 pp. (Ages 12-15)

This strange, contemporary tale involves ghosts that reveal the past and help 14-year-old Tree to understand the present and her older brother Dab who is retarded.

Hirsch, Karen. MY SISTER. Carol Rhoda Books, 1978.
Unpaginated. (Ages 6-9)

A young sibling talks about the special problems and joys of living with a sister who is mentally retarded.

Little, Jean. TAKE WING. Little, Brown & Co., 1978.
176 pp. (Ages 9-14)

Laurel Ross knows her younger brother James is different, but their parents have not yet acknowledged his retardation. Events change all of them.

Reynolds, Pamela. A DIFFERENT KIND OF SISTER. Lothrop, Lee & Shepard, 1968. 193 pp. (Ages 9-14)

Thirteen-year-old Sally Barnes' sister, 18-year-old Debbie, has come home to live after four years in a school for people with mental retardation. Sally's summer revolves around a horse, a race, new friends, and, of course, Debbie.

Rodowski, Colby F. WHAT ABOUT ME? Dell, 1976. (Ages 12-15)

A frank, sometimes unrelievedly honest account of the difficulties and problems of 15-year-old Dorrie, whose younger brother has Down's syndrome, clearly delineates the negative feelings that siblings of a retarded child may experience.

Shyer, Marlene Fanta. WELCOME HOME, JELLYBEAN. Charles Scribner's Sons, 1978. 152 pp. (Ages 12-15)

Twelve-year-old Neil writes of the drastic changes faced by his family when his sister who has spent nearly all of her 13 years in institutions comes home to live. The events are sometimes amusing, sometimes upsetting, and usually believable.

Smith, Lucia B. A SPECIAL KIND OF SISTER. Holt, Rinehart & Winston, 1977. Unpaginated. (Ages 5-9)

Seven-and-1/4-year-old Sarah shares her feelings about life with Andy, her retarded younger brother.

Sobol, Harriet Langsman. MY BROTHER STEVEN IS RETARDED. MacMillan, 1977. 26 pp. (Ages 6-10)

Eleven-year-old Beth talks frankly about life with her older brother Steven who was brain-damaged during the birth process. Black and white photographs illustrate the simple, truthful text.

Wright, Betty Ren. MY SISTER IS DIFFERENT. Raintree, 1981. 31 pp. (Ages 5-8)

Carlo learns some important truths about all his feelings toward his older sister Terry, who is mentally retarded, when he loses her in a department store.

Compiled by Cory Moore, Family and Community Resources, Montgomery County (Maryland) Association for Retarded Citizens, 11600 Nebel Street, Rockville, Maryland 20852. (301) 984-5792.

BROTHERS AND SISTERS OF HANDICAPPED CHILDREN IN FOSTER CARE

- Sharon J. Young

A handicapped child is born or diagnosed. A dream dies. A mourning process begins. The struggle has already begun to obtain services that are appropriate for the child and supportive to the parents. However, it is not only the handicapped child and the parent whose life has been touched, it is the lives of everyone in the family. Both the current and future normal and/or other handicapped children in the family will be affected.

This paper will demonstrate how one Residential Treatment Center choose to serve the siblings of their severely developmentally disabled brothers and sisters. It will also share our discoveries and their implications for providing services to this population.

Mercy Home for Children is a small residential treatment center for severely developmentally disabled children and adolescents. We provide 24 hour supervision in a maximal structured setting for 60 residents. We service moderate to profoundly Mentally Retarded, and Autistic children and their families. Our resident population ranges in age from 5-16. The majority of our children were placed voluntarily by their parents(s) because they could no longer cope with the demands of their handicapped child. Again the majority of our population will require some type of supervised living environment built into their adult lives. Our sibling population is 50 representing 36 families. Thirty-six siblings are currently under 13 years old. Fourteen siblings are 13 or older.

In January and May of 1983 the agency provided its social workers and some parents (January) an opportunity to attend the conferences on the Siblings of the Mentally Retarded and Developmentally Disabled. Through these conferences we became aware that we were in a unique position. The conference's focus was on siblings in their twenties to thirties struggling to obtain services for their disabled siblings who were aging out of current programming. Other concerns presented were that of agencies trying to keep their Adult Mentally Retarded client in touch with their families. Our families are travelling on a different course. Placement occurred early in the family history after the family was unable to cope with the demands of the handicapping condition(s) and/or behavioral difficulties presented by the severely disabled child. We are looking at our families from a different perspective. Our challenge has been how to help our families mature bonded. Our focus is upon what services will enable us to accomplish this goal.

Our agency decided to apply for a grant from New York State Council on Developmental Disabilities to fund a pilot program

for our siblings. The grant was to provide Group Therapy, individual or family therapy, and a Resource Room. The Resource Room was to be a place where the brothers and sisters of our residents could go to find materials on the developmental disabilities. We were successful in obtaining this grant. The starting date for our program was December 1983. The program was funded for one year.

During the late Summer and Fall of 1983 I met informally with siblings during a parent support group to obtain information about what they would find helpful. This assessment revealed their needs to be: (1) Socialization, (2) Peer support and (3) A place to talk and get answers about the handicapping condition of their brother or sister.

In view of these needs the group was then structured to be an open group rather than a closed group. It was also designed to be an activity group rather than a "talk" group. A sibling could be a part of the group as long or as short a time as needed, or could be tolerated. Siblings of newly placed children could join the group without a waiting period i.e. waiting until the next cycle begins. A sibling could easily rejoin the group after an absence.

The group composition is heterogenous in terms: (1) the severity of the disabled sibling's handicap, (2) the position of the well sibling in the family, (3) family size, (4) socioeconomic status, (5) the number of handicapped children in the family, (6) the length of placement, (7) the well sibling's attitude toward the disabled sibling, and (8) the family's visitation plan. Despite these many differences the commonality of having a disabled sibling in placement has made the group a cohesive one.

The severity of the disabled sibling's handicap ranges from moderate to profound Mental Retardation and Autism. Secondary diagnosis includes seizure disorders, and Cerebral Palsy. All are ambulatory. Out of the 13 families being served by this grant only four families have verbally handicapped youngsters.

The sibling in the group represent the oldest, middle, youngest and the other twin in the family. They have other well siblings, only the disabled sibling or in one family's case the well sibling is the only non-handicapped child in a family with three children. The length of the placement of the handicapped child also varies between as long as 6 years to a time span of less than a year. Siblings attitudes toward the disabled sibling ranges from disgust to an acceptance and understanding of the disabled sibling.

The last variable is the family visitation plan. This also is very different among our families. There are families that visit only at the agency from once a week to once a month. The siblings may or may not be included in these visits. Other

families take their handicapped member home once or twice a month. Some visit overnight or for a week-end. Others have day visits at home or combination of day and overnight visiting.

I. The Conduct of the Group

The group sessions are held twice a month on the weekends i.e. the second Sunday and fourth Saturday of each month. The sibling group meets simultaneously with parent support groups. The meeting days and times were chosen by the parents. Doing the groups simultaneously aided attendance in both groups. The group sessions run an hour and a half.

The group runs as an activity group. During the course of our six month existence we have done a variety of projects i.e. painting, puppet making, wooden figures, macaroni crafts and tray art. There are two to three activities during each session from which the group members make a choice.

To date there have been two themes to the group. One "getting to know one another" and "Team Work". The first formal 3 months of the grant we designed and completed many projects and talked. Some of the issues explored were the level of functioning of their handicap sibling, a variety of behavior modifications techniques used by staff or the handicapped sibling, agency visits and home visits, reactions of parents to visits, how the well and disabled sibling play and the reaction of friends to the disabled sibling. The youngsters often spoke freely about themselves and the things they like to do, apart from their disabled sibling.

The second theme of the group "Team Work" coupled the well sibling and disabled sibling for a specific project. They prepared art work for the Very Special Art Festival at Columbia University, Washington D.C. and the Mercy Home. There were many surprises during the preparation for the festival. No sibling in the group thought of or designed projects for their disabled sibling which was above their functioning level. Many group members persevered under trying conditions i.e. their siblings short attention span and hyperactivity hindered the amount of work which could be accomplished in one sitting. Most completed their project with pride. Those that were unable to finish due to the disruptive behavior of their sibling were supported by their peers for the effort and encouraged to complete the project for a later display or take it home.

During the first six months of the project I have noted that (1) siblings know a great deal about the handicapping condition of the disabled sibling. They do not have the medical or behavioral labels, however they do have the ability to describe in detail the functioning level of their sibling. During our discussion on projects for the Special Art Festival one 6 year old stated "We got to find something real fast for

my brother to do. You know he can't sit long." A 12 year old stated "My brother is into smearing. He and I can do something like finger painting." (2) They are willing to talk about their handicapped siblings and their relationship with them. Both the positive and negative aspects were expressed. They were supportive of each other when discussing the handicapped sibling yet were attacked at times when discussing personal likes, dislikes or opinions, apart from the disabled sibling. Statement such as "My brother really drives me up the wall when he make those awful noises," was responded to like "Your brother makes that sound. Hey, I thought my brother was the only weird one." Esther told Alex "Isn't it embarrassing when you're in the street and your brother starts to bite his hand. Isn't it the pits." Alex started to shake his head "No" - but looked at Esther and said "Yes, I want to sink in a hole but it's not his fault." (3) There were many unanswered questions which the sibling felt free to ask concerning mental retardation, autism, cerebral palsy and seizure disorders. Along, with questions about their sibling not speaking, not being toilet trained, biting their hands and banging their heads. Sometimes they were able to answer the questions among themselves. Other times they needed my assistance. The point that was clear was that this was the place to ask the questions and to get the answers.

II. Implications

During the course of the project I have observed that it has been a positive force. As the project continues I am sure our thinking on many issues will be refined. To date my observations have suggested the following implications. First, this type of project will aid our siblings hopefully decrease the emotional difficulties experienced in two ways: (a) it will offer support for those who need help getting through "the rough spots" and (b) provide us (the agency) with a screening ground for those who will require more intensive therapeutic intervention. Second, I see the bond of sibling to sibling just as important as parent to child if the family is to mature and emerge as a intact unit. This program works on the sibling to sibling bond. Families who are bonded in a positive manner are better able to handle life's difficulties. The emotional quality of life is improved for all family members. Third, I see this as a start to community education. If the handicapped person remains an integral part of the family's life their Community (Extended family, friends, neighbors) will be exposed to the handicapped person. Their ideas and attitudes will be shaped by the stories they hear as well as the actual experience with the handicapped person. Exposure to handicapped people and/or families with handicapped person in them is a must for the start of better community understanding of the handicapped. The fourth implication is from a long term perspective. Children who have grown up involved but not burdened by the care of their disabled sibling may be more likely to remain involved as an adult. As adults they are perspective voters

and can be an effective lobbying force for maintaining current programming and obtaining new ones for the disabled person in their family.

In summary, the group has been a positive experience for both the siblings and I. The group members have enjoyed each other and have experienced some unexpected unimagined fun with their disabled sibling.

The experience has also been difficult and trying. It has required a great deal of stamina and imagination on both our parts.

SOME OBSERVATIONS CONCERNING JEWISH SIBLINGS

- Clara Horowitz

After nine of anticipatory waiting, a period invested with hope and fantasy about the baby who will assure their continuity and fulfill their dreams, the new parents learn that their baby is "not normal." This is a nightmare of crushed hopes from which there is no awakening.

Unlike the recent past, these parents today are less likely to be urged by professionals to leave their baby in the hospital and to "forget" its existence. Attitudinally, however, what these new parents are faced with is not so very different. Instead of the shower of joy, gifts and congratulations with which parents of a neonate typically are greeted, friends and relatives alike react with pity, sorrow and avoidance as well as, too often, also disappointed anger. I quote from a letter to Ann Landers published just weeks ago:

"My mother came to see me in the hospital when the baby was twenty-four hours old. They took her... to see her grandson... ...she returned to my room white as chalk... and uttered a single sentence that devastated me, "You must have done something terrible or God would not have punished you this way..."

Most people's manners and empathy cause them to cover their feeling with a more polite veneer. There is, however, no concealment from these new parents that the expected happy "Blessed Event" has turned instead to the bitter ashes of tragedy. Not only are they left to mourn the death of their unborn fantasized "perfect" baby, but added to their pain resulting from the devastating destruction of their hopes, is the frightening specter of anxiety for what the future holds. Instead of the jubilant parenthood for which the pregnancy had held so much promise, they have become survivors of their own private Holocaust. They begin the never-ending process of grieving for the fantasied child they have lost. In time, thin, easily bruised away, layers of scar tissue are developed, but their basic pain and mourning never totally is eradicated.

Traumatic as this experience is for parents of a first baby, the situation becomes even more complicated when, as is more typical, there are still quite young, older children in the family. These siblings often have to cope with the confusion and shock of discovering that mommy's return from the hospital with the new baby is not the joyful experience for which they had been prepared. Instead, inexplicably, their parents are depressed, sad and irritable.

The advent into the family of a developmentally disabled child forever changes that family. Parents never cease their mourning, though it can take different forms over the years. Siblings, likewise, are left with their own sadness and confusions.

Given these realities, it is not suprising that many of the dynamics encountered in families of developmentally disabled persons bear remarkable resemblances to those families of Holocaust survivors.

Like Holocaust survivors, parents of developmentally disabled children bear permanent scars of trauma. For the Holocaust survivors, the scars were inflicted by losses of homes and family, cruelty and inhuman victimization. For the parents of a developmentally disabled child, the trauma caused by lost dreams and victimization by a society that is only slowly moving away from medieval, cruel, stereotypically negative attitudes toward those of its members who are different.

Among the Holocaust survivors there are those who have been crushed into psychopathology by the weight of their horrendous losses and experiences. However, there are also those hardier, courageous survivors whose struggles post-liberation continue to be centered on a demonstrated feeling of obligation to give meaning to their lives. These latter are analogous to the committed parents of developmentally disabled children who dedicate their lives to the pursuit of, and struggle for the creation of needed, appropriate services for their own and other people's developmentally disabled children.

Their normally endowed children, like those of Holocaust victims, often are left with many unanswered questions, as well as their own confusions, and mixed feelings. Quickly sensitized to their parents' pain, too often they repress their questions, not necessarily because of parental unwillingness to provide answers, but out of their own concern lest they cause their parents yet additional pain. The taboo, rarely talked about, subject, coupled with guilt over hurting their parents and wishing to protect them from further pain, in both populations, leaves these siblings with unrealistic, extensive, and often frightening, fantasies. Normal sibling rivalries become overlaid with additionally heavy tiers of guilt as these children resent what they perceive, often with justification, as their parents' diminution of time for them as the needs of the developmentally disabled sibling absorbs so much parental physical and psychic energy. This becomes even more painful as they are subjected to teasing and taunting from peers about their sibling's differences -- this last phenomenon not too unlike the Holocaust survivors' children being taunted with, "Your parents should have been burned in the ovens!"

At different developmental stages, siblings' anxieties and questions vary. For young children, they include such terrifying thoughts as: Is my sibling's disability my fault? Did I somehow mysteriously cause it? Is the condition catching, like measles? Will I at some point, like a chameleon, change from who and what I am to become like my disabled sibling? Will I be punished for resenting my sibling? Unable to seek answers from their parents, the child confides his anxieties to a "best friend" - and, when the friend tells other children, the search for peer support often subjects the child instead to taunts from peers, thus compounding the cycle of fear and pain.

As siblings grow into adolescence, a period at best fraught with conflict and insecurity, additional anxiety and guilt-producing burdens can be added. Will the opposite sex reject me because of my sibling? Is this a hereditary condition? Will I also parent developmentally disabled children?

Superimposed on all of this normal, if somewhat differently focused, self-questioning of the adolescent, a phenomenon universal to growing up but again complicated by the need to protect parents from pain, is the feeling, regardless of its validity, of parental expectation of achievement to compensate for the deficits of the sibling. This also parallels the Holocaust's survivors' children's feelings about parental expectation to compensate for Holocaust-related suffering and deprivation.

Adolescent rebellion, the normal accompaniment of the growth struggle for individuation and separation in preparation for adulthood, similarly may be inhibited in an effort to compensate for parental pain or exaggerated in an attempt to become "one's own person."

The placement of the developmentally disabled sibling away from home, even when patently for the purpose of offering peer and growth stimulation to that sibling, also has potential for creating emotional crises. Especially for the young child, placement of the sibling rival away from home can experience as guilt-producing wish fulfillment. In addition, it raises the fearful specter that, if this rival for my parents' attention can be removed from the household, might not I too be "sent away?"

Feelings about the placed sibling may be handled in a variety of ways. Some use avoidance: they do not participate in visits to the group home and try to absent themselves as much as possible from home when their siblings visit overnight. As the circle of firends widens and the dating process begins, some may even keep the fact of a placed sibling a secret. Others become early advocates for services, like one

little 12 year old with whom my agency has worked, who on her own initiative wrote the President asking for expansion of adult services for her brother and people like him.

Among the tragic accompaniments of the most severe forms of intellectual and/or physical impairments is the lack of capacity for maturation into independently functioning adulthood. This precludes the usual progression from infancy to childhood, puberty, adolescence and ultimately adulthood with the regeneration of the cycle into marriage and the establishment of a new family. As parents age and begin to face their own mortality, their anxiety for the ongoing care and protection of their still dependent offspring, regardless of age, increases. Grown "normal" siblings may, willingly or otherwise, inherit these responsibilities after the incapacity or demise of parents.

Just as children of Holocaust survivors often fall heir to their parents past suffering and become imbued thereby with special sensitivities and related sense of mission, siblings of disabled individuals likewise can become similarly invested in the cause of assurance of community understanding of and development of services for this needful group. This conference and the development of such organizations as Siblings for Significant Action are testaments to this fact.

In conclusion, as described in this paper, the birth of a developmentally disabled child results in so many interfamilial shifts that the family is forever changed.

BIBLIOGRAPHY

- 1) "Parental Dilemmas," Lessons I have learned in Interacting with Parents.
- 2) "Implications of the Holocaust for Social Work"
Maria Rosenbloom.
- 3) "Grieving Over the Lost Dream"
Audrey T. McCullum, The Exceptional Parent Magazine 2/84.
- 4) "Children of Survivors of the Holocaust, A Critical Review of the Literature"
Norman Solkoff, Ph.D., American J. Orthopsychiatry 51(1) 1/81.
- 5) Ann Landers' column, "The Pocono Record," 5/11/84.
- 6) "Respite Program: Services to Developmentally Disabled"
Shirley Tolchinsky, CSW, Prepared for Presentation at the 1984 Annual Conference of JF & CS Agencies, 5/2/84.

LIFE STYLE DEVELOPMENT OF SIBLINGS OF SPECIAL NEEDS CHILDREN: AN ADLERIAN APPROACH

- Barbara Fairfield

I. Introduction

The "life style" of an individual refers to the personality of an individual including his/her unique attitudes, perceptions, conclusions, etc. about life. Alfred Adler viewed individuals as striving to overcome a feeling of inferiority and insecurity about their place among others (1). A person compensates for this felt inferiority by moving in a direction that he/she perceives will result in a more secure and superior position with respect to other people. Adler's theory stresses the self-determination of the individual based on his/her own unique perceptions of life as experienced in the family environment during the early years of childhood. The movement of an individual always makes sense, but only if viewed, as it were, through the eyes of that person as he/she grew up in a unique family, culture, milieu, etc. In order to understand the disturbances of individuals, then, it is necessary to understand how they come to view life and their place in it.

The family who has a child born to them with special needs presents a unique environment which each family member will react to either in accord with his/her already developed style of life or, if a young child, in such a way as to develop a style of life (2). Adler's theory allows us to examine the movement of siblings who grow up in these families to come to a better understanding of how they may view life and thereby understand the influence such a unique family environment may have in their lives.

II. Place in the Family

Most persons when asked "who was the most important person in your development?" will respond, "my mother" or "my father." Although mothers and fathers are very important to development, it is likely that the most important person in an individual's life is the brother or sister most different from them (and for an only child, the absence of any siblings). For a brother or sister of a disabled child, the handicapped child will often be the "most different" and as such easily serves as reference point for the other siblings' development of a style of life. Parents tend to reinforce the conclusions drawn by their children regarding each child's place in the family - e.g. by praising the "good" child, punishing the "bad" child, laughing at the "clown," etc.

For families without special-needs children, the actual birth order of the child may give a likely basis for

understanding the child. First born children, for example, tend to try to live up to their parents' expectations by being responsible, high achievers, etc. Second born children tend to be highly competitive, trying hard to overcome the first born's excellence. Youngest children have a tendency to seek special service and attention, etc. But if a special-needs child is born into a family, the actual birth order may be less important than the fact of the child's special problems and how the other sibs perceive themselves in relation to that fact. For example, if the handicapped child is the first born, a subsequent child may respond by meeting the parents' failed expectations for their first child. He/she may then assume more characteristics of a first-born responsible, over-achieving child, or he/she may regress and develop areas of need in order to secure the parents' attention becoming psychologically more like a youngest. The place in the family, therefore, of the normal sibling has to be examined carefully in order to understand the subsequent movement of the child.

Typically parents are unprepared for the birth of a disabled child. Initially they may experience shock and numbness which other normal siblings in the family may perceive as distancing or even abandonment. The needs of a disabled child present many new tasks to parents who understandably become preoccupied with doctors' visits, hospitalization, early educational intervention, various therapies, etc. for their handicapped child. Like any normal child, the non-disabled sibling is already facing the challenge of finding a place in this family, but now another threat has emerged in the person of their disabled sib. Many a normal sib will compensate for the felt slight and sense of unimportance in one of three ways:

- (1) by becoming overly-responsible, the "good" child so as to win the parents' notice and approval;
- (2) by becoming needy themselves in some area, such as school achievement or social adjustment;
- (3) if very discouraged, they may become resentful and revengeful toward their disabled sib, the parents or others; or
- (4) if completely discouraged, they may give up all together on life.

III. Family Atmosphere

Siblings are influenced in their choice of compensatory movement by the family atmosphere which is usually a reflection of the family values. A family atmosphere of achievement and high standards, for example, might lead a child to decide to compensate by being a high achiever themselves or oppositely, to underachieve so as to gain parental attention. An atmosphere of overprotectiveness might influence a sibling to become

overly responsible as a way to belong in that family. An authoritative atmosphere may encourage a child to become bossy towards others or to engage in power struggles in order to be reckoned with. The following is a list of typical family atmospheres according to Dewey (3) and their positive counterparts

- rejective - accepting
- authoritarian - democratic
- martyrdom - self respecting
- inconsistent - clear, orderly
- suppressive - open, demonstrative
- hopeless - optimistic
- overprotective - responsible
- pitying - encouraging
- high standards - acceptance of mistakes
- materialistic - relationship oriented
- inharmonious - nurturing
- disorderly - orderly
- overorderly - orderly, but flexible

IV. Level of Family Cooperation

In addition to the place in the family and the family atmosphere, the degree of cooperation within the family based on the amount of mutual respect for family members and the sense of worth or equality of value of each person influences each child's development. Of primary importance is the model of cooperation that the parents present in their own marital relationship. How parents cooperate with the children either by dominating or pampering the children or by treating them as important in family decision-making through democratic techniques of child-rearing (4,5) is another factor in the child's development of appropriate interactions with his/her sibs. A normal sib of a disabled child who is encouraged to participate in the family by contributing his/her ideas and voicing concerns is more likely to feel there is a place for them in the family and less likely, therefore, to compensate in extremely negative or overly-responsible ways.

V. Practical Implications for Families

It is obvious that parents cannot prevent the disabled sib from having an impact on the development of their other so-called "normal" children. However, if parents (and professionals) understand the life style influences on children, they may maximize the degree of courage and cooperation among the siblings. Instead of reinforcing the overcompensatory behaviors of their children, parents will not praise the overresponsibility or "goodness" of the child, but instead will acknowledge the specific contributions of each child in the family. Parents can try to offset the extra attention that is required for the care of their disabled child

by setting aside special time weekly or daily for interaction with each child in the family. Parents will expect that the children have reactions to their disabled sib, for example, jealousy, embarrassment or anger. Appropriately, parents will make guesses with their children about specific feelings they might be experiencing, encouraging the children to deal with these feelings openly in the family. Finally, parents will find a way to include all the children in family problem-solving. Many families do this through weekly family meetings (4).

VI. Summary

Siblings of Special-needs children, like all siblings, develop their style of life or approach to life in a family context. For the sib of a disabled child, however, the family milieu may be disturbed by the unexpected event of the birth of a handicapped child.

In view of the special attention paid to the disabled child, the other siblings may question their own place in the family. This discouragement of the normal sib may lead to overcompensation by becoming overly responsible or overly needy.

References

- (1) Ansbacher, H.J. and Ansbacher, K. The Individual Psychology of Alfred Adler. New York: Harper and Row Publishers, 1956.
- (2) Fairfield, B. "Life Style Issues of Special Needs Children and Their Families" Individual Psychology, 39 (4), December 1983.
- (3) Dewey, E.A. "Family Atmosphere" in Techniques of Behavior Change (Nikely, A.G., ed.). Springfield, Ill.: Charles C. Thomas, 1971, pp. 41-47.
- (4) Dreikurs, R. Children the Challenge. New York: Hawthorn Books, Inc., 1964.
- (5) Yura, M.T. and Zuckerman, L. Raising the Exceptional Child. New York: Hawthorn Books, Inc., 1979.

INSTITUTIONALIZATION AND SIBLINGS: WHAT CONSTITUTES CONTINUING RESPONSIBILITY?

- Carol Sussman & Mary Wolfe

This paper, which concerns itself with the role of siblings with regard to their institutionalized mentally retarded brothers or sisters is based on our experiences at Letchworth Village Developmental Center.

The Welfare League, Letchworth Village Chapter of the New York State Association For Retarded Children, was formed in 1939 by the parents, relatives and concerned friends of the mentally retarded people living at Letchworth Village Developmental Center. It was organized with the express purpose of protecting and promoting the health, safety and welfare of all the residents living at the institution. In 1976, Welfare League was named the Official Parent Advisory Group for the institution by the former Department of Mental Hygiene (now the Office of Mental Retardation and Developmental Disabilities). Throughout the years, Welfare League's lobbying efforts have contributed to the betterment of the conditions at Letchworth Village and the care of its residents. The Welfare League has also raised funds to purchase equipment and services in order to improve the quality of life at the facility. In 1977, Welfare League initiated the Special Services Project which provides consultation and assistance to families and residents in matters of habilitation planning and community placement. The Welfare League also acts as the correspondent for all residents who no longer have family members who can represent them. Parents and siblings continue to view the Welfare League as an objective resource to whom they can turn for guidance and help with regard to the care and well-being of their mentally retarded relative.

Letchworth Village opened its doors in 1911. It is a residential facility for the mentally retarded situated in the beautiful Ramapo Valley of Rockland County. In the late 1960's and early 1970's, Letchworth Village had a population of 5,000. With discharges of the higher functioning residents in the early 1970's and subsequent on-going efforts at deinstitutionalization, Letchworth Village currently has an on-campus population of approximately 1,500 individuals. As a Developmental Center, Letchworth Village is not only responsible for providing health and habilitation services to its residents, it must also provide a less restrictive and more normal living environment for all who live there.

The current population ranges in age from a small group of multiply handicapped children to adults whose ages range up to 94 years. Letchworth Village is unitized into 6 Units. In Summit Unit, there is a concentration of elderly residents; of our 275 residents, 180 are over 55 and 95 of the 180 are at

least 70 years of age. The range of retardation varies throughout the institution; however, the vast majority of the residents have I.Q.'s below 40, and some have maturational ages as low as "below one year." This places most of the residents in the severe or profound ranges of mental retardation. I.Q. is only one tool to measure functioning level and many of the residents, especially those who have had ongoing family contacts, do have good social skills and/or good self care skills despite low I.Q. scores.

Most residents live in cottages rather than in multi-storied buildings. In the old days, these cottages housed a many as 100 residents; today they house 25 residents and the hope is that as more people are placed in the community, these cottages will house only 18 persons. There are ongoing changes with respect to on-grounds/off-grounds programming. Letchworth Village currently has a mix with the current trend being centralized programming within each unit for those who do not go to off-grounds programming.

For the most part, brothers and sisters share with their parents the concerns and conflicts that are a part of the retarded siblings impact upon the family. They worry about how to tell their friends, and whether the information will make a difference in their interaction with their peers. They struggle to accept the fact, themselves. They wish to discuss the situation with their parents as full family members, not as protected children who are provided with half truths. Usually, they wish to share in the care of the retarded sibling, but not to the extent that this interferes with their own lives. The siblings, as children, seek guidance as to how to set and maintain limits in order to protect themselves from manipulation and exploitation by parents as well as the retarded person. As the siblings get older, they frequently express concerns about having a retarded child themselves and may seek genetic counseling. Older siblings may have concerns regarding parental expectations in terms of future care and even financial support of the retarded sibling. Emotional concerns may develop for the brothers and sisters as a result of the parents' attitudes and behavior toward the retarded sibling, especially if they feel bound by the parental role model. This often becomes a problem when the sibling's family is scattered over a large part of the country; for example, Florida, California, Ohio, even Pennsylvania can be quite a distance as you become older. Most siblings are anxious to ensure the retarded person's care - their daily care, their health care and to provide their relative with the much valued family contact. It is important to remember that Letchworth Village has a unique elderly population with the majority over 40 years of age. Their parents, for the most part, are over 60 and their siblings are adults who often have families of their own and may live far away. Consequently, these siblings have varying degrees of availability and visibility to their mentally retarded brothers and sisters.

As we tried to organize our experiences and attempt to draw some conclusions about the role of siblings, one major theme kept cropping up which seemed to be a thread tying many of the siblings together. Most siblings have struggled with what their role ought to be with regard to their brother or sister and for the most part, the only model available to them, was the role their parents played. While they had this parental role model, they were not the parents of their mentally retarded relative. How could they develop a role for themselves? What guidelines were available? Most of them had little or no contact with other siblings. In a facility as large as Letchworth Village, the chances of meeting another brother or sister while they were visiting was not great. Even if they did, the concerns that they had were not the easiest to talk about with strangers. The isolation many of these siblings have experienced has made their struggle a difficult and lonely one. Most have had to grapple with what their responsibilities are and what alternatives are available to fulfill them in a responsible fashion.

Who are these siblings? Most of the sisters and brothers we have talked with are middle-aged to elderly adults themselves. A majority of them maintain some form of contact but geographic distance, family responsibilities and, for many, their advanced age make frequent visits difficult. Either they live out of state and visit no more than once or twice a year or if they are within commuting distance, visits may be more frequent but still a hardship if they don't drive. Many of these siblings are the only surviving relatives. In addition, there is another large group of people who are younger (30-40) whose parents are still alive. These siblings visit at times alone or with their parents and indeed, parental visits are sometimes only possible because the sibling is able to transport them. This seems to be the group that is less visible and yet the group of people that probably will need the most support as they begin to face the needs of their aging parents and the eventuality of assuming the primary responsibility of "watching out" for the well-being of their mentally retarded brother and sister.

We have found that talking with the older group of siblings (over 45) that many of them have established a routine that seems to work for them. They visit from twice a year to monthly depending on geography, health, age and, in some cases, the degree of retardation of their relative. Many of these people do not seem to be in conflict; they do what they do and have developed their own patterns. For the most part, conflicts only begin to emerge when they are faced with their own advancing age which prevents them from doing "what they used to do." Illness, difficulty travelling and lack of convenient transportation are several factors that begin to affect their visitation. Another source of stress occurs when they are faced with decisions about community placement. It is at this time, that the recollections of their families against "moving"

the "child" out of Letchworth Village often become a source of terrible stress and fear. It appears that as long as these siblings can follow in the footsteps of their parents, they derive a source of comfort; they have internalized their guidelines from their parent's requests and wishes. In many ways, this has served a positive function in that it has given them some model to follow. On the other hand, however, it has prevented them from recognizing that as they get older, their retarded sibling also gets older and people's needs change and the opportunities (both environmental and programmatic) for the mentally retarded person change also. These siblings are often ill-prepared not because their parents didn't teach them but because times have changed and, consequently, the responsibilities and decisions which they are facing were not even options twenty or thirty years ago. Even so, there are numbers of siblings who do feel that their parents could have better prepared them for their current responsibilities. This highlights their loneliness and their need to communicate with others like themselves who face similar decisions and problems.

The group of siblings, whom we see less often but who we know exist in great numbers, are the younger ones (30-40). Their parents are still alive and follow different schedules of visits. Some of these siblings live within commuting distance and tell us of their struggles about what they can realistically expect of themselves in relation to their brother or sister. They experience pressure from their parents to get involved because the parents will not be alive forever and this produces resentment, guilt, concern and fear in them. These siblings feel isolated from others in the same situation. They do not feel that they want to or can do what their parents may be doing at the current time and yet they believe that anything less is insignificant or inadequate. To make matters even more difficult, the ability to discuss these concerns directly with their parents is not always more difficult, the ability to discuss these concerns directly with their parents is not always what they feel able to do. Afterall, their parents are old and they do not want to upset them.

Siblings have to eventually come to terms with not only their mentally retarded sibling but also with their parents and the parental role model to which they have been exposed. They need to develop their own individual role and they do need to know that different models and alternatives are available. The parental model is not the only model available. The weekly visit is very often the model the sibling is so familiar with (or every other week etc.) but it is not the only one nor should it be. Siblings need to come up with something they can live with that takes into account their own individual needs as well as the individual needs of their retarded brother or sister. It is a difficult struggle and these siblings do need support, guidance, understanding and acceptance. They also need each other to communicate with; they need to distinguish themselves from their parents and establish a dialogue; they

need the support and empathy from professionals in this unique search for a path; and they need alternatives to look at and evaluate for themselves.

There are a number of factors which affect the kinds of alternatives that siblings may select for themselves. For example, the whole living situation of the resident has drastically changed over the years. Residents are busier attending programs and going on community trips. They have their own routine, friends, volunteers (senior companions, foster grandparents) who are an important part of their lives. They are more active and some of them even work and earn money. Consequently, trips into the community which in past years only occurred if parents took them, is not true today. Relatives are not the sole bridge of the retarded person with the community and the outside world. In addition, the changing needs of the residents are important since, as they get older, their abilities and desires change. For example, many families tell us that they take their son (daughter) home for shorter visits because their son (daughter) misses their friends and are bored at home.

There are two major categories of residents we are dealing with at Letchworth Village:

1. The higher functioning residents who can show appreciation and share with the family what is happening in their lives at Letchworth Village; these are mostly verbal residents.
2. The lower functioning residents who are in less of a position to communicate their needs or their appreciation and who are generally less responsive to visitors.

We have already talked about geographic distances and mentioned personal factors such as age, health and other family commitments which become obstacles to frequent ongoing visits. Let's look at some ALTERNATIVE ways of keeping in touch with the institutionalized person in a meaningful way.

The following suggestions for the siblings of the mentally retarded residents offer a variety of alternatives for fulfilling the desired ongoing family contact while, at the same time, allowing the siblings a life of their own. These are "methods" which have been tried, modified and adapted for individual needs, and are working for the residents and their siblings in Summit Unit.

1. THE PLANNED PHONE CALL

Some groups of residents, 4-5 at a time, meet with the social worker in a social situation (tea and coffee served) before the regular phone call is made in order to discuss their current activities - trips, programs,

vacations and health status; we practice conversations through role-playing. In this way, the resident has something to share with his/her brother or sister on the telephone which is much more meaningful than the repetitive "when are you coming?" and "bring me..." or "I want..."

Unplanned phone calls initiated by the resident's family are fine; but the family needs to realize that they must give the social worker time to get answers to questions or to see the resident or to bring the resident to the phone before calling back.

2. LETTERS AND PACKAGES

This works both ways: of course, our residents love receiving letters and packages from their families. We have staff who write letters for our residents and we encourage our residents who make things - handcrafts and woodcrafts, ceramics and plants, and even things put together in the nature programs - to share these with their families. Often on a trip, the resident will buy some item to give to their family; we facilitate the mailing of that package by wrapping and mailing it for them.

3. VACATION POSTCARDS

Again, this works both ways. In Summit Unit, every resident who goes on vacation sends a postcard to their family; if they have no family, a card is sent to someone of their choosing, usually another resident or cottage staff person.

4. PHOTOGRAPHS

Photographs of the sibling, his or her family, house, pet, boat, etc. are helpful to the residents in developing linkage and familiarity. The residents love pictures and when one supplies these photographs, one is sharing one's life with them in a meaningful way. It is helpful to staff if the photographs are dated and the people identified in the photographs. Indeed, it should be noted here that a good photograph of someone they recognize, gives even a profoundly retarded resident great pleasure.

5. LIFE REVIEW GROUPS

We mention this group because it is so very important for siblings, to participate with us to make this meaningful. The Life Review groups are small groups, five to eight persons, who share their life experiences through the use of prompts from old records, their own

recollections and the use both old and new photos sent to us by families. This is a very meaningful way of helping our residents cope with the changes that occur over time; for example, who in their family is alive or dead, who got married, where do they live, etc. and the delight in discovering "I am an aunt or an uncle."

6. USE OF STAFF

This method of keeping in touch is especially important when the retarded sibling is profoundly retarded or multiply handicapped; for example, non-verbal, deaf, blind etc. When one visits one should seek out someone who seems to have a special interest in your relative. This may be the social worker, therapy aide or program person; this can be a wonderful contact for the sibling. It gives the sibling someone to talk to about the institutionalized relative, someone to explore your ideas with, someone to answer questions and someone to be helpful to with respect to: the best time to visit or phone, appropriate and useful articles to purchase, who should break the news of death or illness of a family member, etc. In this way, the sibling becomes a member of the "team" of people who are responsible for providing an environment which will enhance the life of and help your relative to grow.

Finally, it is important to remember that whatever a sibling decides to do, it should be done willingly, with caring and sensitivity, do it on a continuum, and always fulfill one's promises - that is why, whatever one decides to do must be reasonable based on one's time and distance constraints, one's age and health constraints and what one feels would be most meaningful to the institutionalized relative.

We don't think that there is any one answer; we think there are many answers. We have shared some of the ways siblings have been helped to devise a role for themselves and we hope that through this seminar, other ideas will emerge from discussion and mutual sharing.

THE SIBLINGS' PERSPECTIVES:
A VIEW OF THE HANDICAPPED CHILD IN THE FAMILY SYSTEM

- Sharon F. Kramer

The difficulties and opportunities which families experience as they open their lives to a handicapped member have been scrutinized by many. Freud's analysis of the issues provoked by the birth of the handicapped child (Freud, 1917, 1956) provided a theoretical foundation for the work of many (e.g. Solnit and Stark, 1961). Bernard Farber's research served as the start of another era in the field: his work was based on interviews with parents and siblings, and added a new dimension to study of the handicapped family member (Farber, 1960; Farber, Jenne, and Tolgo, 1960; Farber and Ryckman, 1965). More recent writings have increased the diversity among available resources on siblings (Grossman, 1972), on parents (Barsch, 1976), and on the family as a whole (Featherstone, 1980). However, these writings are, for the most part, addressed to academicians and practitioners. Although the questions posed and answered in many of these works are central to the concerns of families and siblings, the language and format tend to obfuscate rather than enlighten.

This paper, based on a formal research study (Farago, 1983), provides an alternative to traditional forms of information dissemination. Readers who are interested in extensive details regarding the study design and theoretical foundation are directed to the work cited above.

The process of living in a family with a handicapped member is complicated by ambivalent feelings, by demands on resources, by isolation. This paper is designed to use the work of R.F. Bales (Bales, 1970; Bales and Cohen, 1979) to formulate four basic questions, which can be used to assist families in looking at their own family situations. The questions will be discussed, used to present the findings from the FAR Study, and then to provide a means of generalizing from the FAR Study to future work with families which include a handicapped member.

I. Questions Which Address Family Life

The following four questions can help family members to take a look at the ways in which their family functions and help the family to tap into previously unidentified resources. They can also be used by professionals to consider strengths and weaknesses of families.

A. Who is in charge?

This question is one which deserves much study. A spontaneous answer from many people would probably be "the

parents:" however, this is not necessarily the case. In some families, siblings join together to serve as a separate power base (Bank and Kahn, 1982). In other families, a sibling may take on the role of the parent, enforcing rules which have been established by the parents (Sutton-Smith and Rosenberg, 1970). The effect of parental responsibilities resting in the hands of an immature person can be problematic both for the child experiencing the responsibility, and for the siblings in the child's care (Rosenbaum, 1963).

Patterns of parental responsibility assigned to a sibling in the family can be especially difficult when there is a handicapped child in the family. The so-called parental child may take up the burdens and responsibilities of the parental role with ambivalence, pride, and worry. The parental child may find it hard to seek assistance and the support available to the children by the parents may not be utilized.

In some families with a handicapped member, the person with special needs may have the most power in determining what happens in the family. The family may be reacting, in an unplanned way, to the person with disabilities, turning the position of authority in the family into a real trouble spot. Examination of leadership in the family with a handicapped child is one with many subtleties, and this question can provide a useful starting point for this examination.

B. Who contributes what?

The media has portrayed families in stereotypic ways which makes the definition of "contribution" very limited. "Contribution" can be seen on television and in other public situations as being very literal: bringing home paychecks, doing the laundry, running errands, making dinner. A family with a handicapped child, however, must develop a very different way of eliciting and valuing contributions, such that all members can contribute. For example, in one family, the beautiful smile of the handicapped child gave family members a sense of that child's contribution to the family. In another, a totally non-verbal child sweeps carefully and well: the family members value the contribution, even though it takes much longer than it might if another family member had done it. In a third family, the child who is the "little firecracker" is seen as a help instead of a hindrance: the child serves as an emotional lightning rod for the whole family.

The redefining of "contribution" in terms of a family's strengths, resources, and needs is an exciting process: it assists the family in the development of internal possibilities. Instead of looking at what cannot be, the family can begin to organize around constructive realities, rather than around impossible burdens for certain members of the family system.

C. How do we show we care?

The demonstration of feelings can be difficult for some members of a family, sometimes resulting in an absence of expressed love and concern. The ways in which family members value those members who can more easily show feelings, especially in light of the day-to-day difficulties which are experienced, can be useful in an analysis of the family system. The ability of one member to express feelings openly can enable others to identify and share what they are feeling.

This question is of particular value for families with handicapped children, as will be shown in the results presented below. The capability of the handicapped children to express feelings can be seen as of value by some families, and thus can help to redefine the kind of meaningful contribution which the child can make to the family system. For the family in which the expression of care is difficult, or undervalued, the handicapped child may have an even more difficult time becoming a contributing member in the family system.

D. How do family members balance each other?

T.H. White referred to balance as the sixth sense: as a triumphant achievement on the part of a young child when the child learns to stand, and then walk. Learning to walk, or to ride a bicycle, are skills which take time to acquire. When they are accomplished, they are rewarded. Balance differs in the family system. It is never fully "learned" because the family is always in motion. Balance in the family is always precarious.

The balance created in a family with a handicapped child is by its nature unique. Developmental limitations, medical priorities, social constraints, and other pressures impact on the family with a handicapped child, affecting the family's balance. The method used in the study forming the basis of this paper provides one way of measuring the family's ability to balance, and to evaluate the congruity which exists between the ways in which different members of the family perceive an individual member of the family system. This can assist the family itself to work more functionally, and draw on its members for different strengths.

II. The FAR Study: An Excursion into the Lives of Families

The FAR Study is based on meetings with 87 families from Indiana and Illinois. Each family was composed of two parents, and three or more children who were each biologically related to both parents. The family members used an adjective rating scale to rate each other. For the purpose of this part of the study, ratings of a single member of the family were used. One-third of the families had a child who had been diagnosed as

Moderately Mentally Retarded. These children were matched to a child in the other two-thirds of the families, who were not Mentally Retarded. The children were matched on the basis of age, gender, birth order, and family size. The children who were the focus of the study were between the ages of 6 and 16. All the families were similar to each other economically.

The FAR Study gave family members an opportunity to think about, and rate each other, using a standardized instrument. The instrument used was a version of the SYMLOG form which Bales had developed to help groups study themselves (Bales and Cohen, 1979). The FAR instrument was a Family Adjective Rating scale, developed by Dr. Bonny Parke, and designed to be used by persons at or above a third-grade reading vocabulary. In general, families were positive about the experience of participating in the study, and viewed participation as a preliminary step in finding out more about the way family members are perceived by each other.

The model Bales developed for looking at groups was based upon three factors, which Bales had identified early in his career (Bales, 1950, 1976) as being central to effective group functioning. The factors coincide with the questions raised above, and serve as the focus for a discussion of some of the findings of the study. The first factor is a continuum of Dominance to Submissiveness, ranging from adjectives such as "active" and "outgoing" to "acts shy" and "quiet." This factor is related to the first question posed above, Who is in charge? The issues of leadership perceived by siblings and by parents were seen differently, and this can be helpful in getting a clearer picture of siblings' perceptions. The second factor is a continuum of Friendliness to Unfriendliness, ranging from adjectives such as "friendly" and "fun to be with" to "unfriendly" and "wants to be alone." The Friendliness factor is related to both the questions of Who contributes what? and How do we show we care? in that Friendliness can be a contribution made by a handicapped child to the family system. The third factor is a continuum of Task Orientation (Instrumental) to Process Orientation (Emotionally Expressive). The task-oriented part of the continuum is oriented toward work-related items, such as "says what to do, organizes activities" and "works too hard at tasks," allowing for both positive and negative feelings toward work. The process-oriented part of the continuum focuses more on feelings, including items such as "playacts or makes believe" and "quietly happy, pleased." This factor relates most to the final question, How do family members balance each other? and provides a way of looking at the family members in relation to each other.

III. The FAR Study's Findings: Some Answers to the Questions

The results of the FAR Study are presented in detail elsewhere (Farago, 1983), along with more detailed descriptions of the study design. The summary presented below is designed to address the four questions posed above, using the results of the FAR Study to pose further questions about additional research which would be of value.

A. Who is in charge?

As measured by the FAR Study, fathers viewed handicapped children to be significantly more submissive than non-handicapped children ($p = .012$), but mothers, siblings, and the family as a whole saw no differences between handicapped and non-handicapped children in terms of dominance. The perceptions of the fathers may reflect one of a number of things: the fathers' relative distance from the nexus of the family system, their influence on the handicapped child (e.g. the child is better behaved when the father is around), their expectations of the child. Further study of the perceptions of the fathers would be needed to pinpoint the origins of the differences.

The absence of a significant difference with regard to the perceptions of siblings may indicate that the handicapped child does not take a dominating, center-stage role in the family. The absence of a significant difference may provide some relief to families with young handicapped children, in that the child's needs and activity level will not necessarily be perceived by siblings as taking over the family.

There are further questions which can be investigated with regard to who is in charge: Does the age of the child influence the way the behavior is perceived by members of the family? How about the gender of the child? Of the sibling? What difference, if any, do the educational experiences of the parents have on the way in which the child is perceived? These questions are currently being investigated. The basic question, of who takes charge in the family system behaviorally, and how that pattern is influenced (directly or indirectly) by the handicapped child, is one which requires further study.

B. Who contributes what?

The contributions made by the handicapped children in terms of friendliness and cooperativeness were identified by the siblings. Siblings of handicapped children rated their handicapped family member as significantly more friendly and cooperative than did siblings of non-handicapped children ($p = .0001$). This perception was also shown in the ratings of the family as a whole ($p = .001$), but neither mothers nor

fathers perceived any significant differences between siblings who were or were not handicapped with regard to friendliness.

This finding is important in terms of the ways in which siblings can be seen to view the contributions of their handicapped family members. Whether the perceptions are due to more contact hours in potential play opportunities, lower expectations of siblings, identification of capabilities of the handicapped siblings, or a less judgmental nature, siblings are able to accept a dimension of their handicapped siblings which remains invisible to their parents.

Additional research on this topic would be of great value, both to possibly corroborate the views of the siblings through more objective measures, and also to view the expanded ways in which family members can usefully contribute to each other, with regard to affect, and non-task-oriented roles. The findings indicate that siblings are seeing something which parents are not seeing. This provides a hopeful sign for families in terms of the positive views of each other which may be able to be articulated by some, but not all, of the members, and then ultimately shared.

C. How do we show we care?

Caring can be shown both in terms of overt demonstrations of friendliness, and in terms of sharing emotions. The finding that siblings view their handicapped siblings to be more friendly than non-handicapped children in other families may show something about the ways and means that care can be expressed in a family with a member who had limited intellectual functioning. Clearly, the expression of care will look different and be experienced differently by members of the family. One point which was eloquently made by Josh Greenfield was that children who are born into a family in which there is a mentally handicapped child experience that as their norm:

I asked Karl: "What does it feel like being in a family with a brain-damaged brother?"
Karl shrugged. "I don't know what it feels like being in a family without a brain-damaged brother."
(Greenfield, 1978)

The siblings may be better able to accept features of the handicapped child than the parents.

The findings of the study indicate that expressing care in a family with a handicapped child is not easily measured or understood. More must be done to find out, and document, the complexities of emotions which family members have in terms of expressing care when a member of the family is less able to express care in words and thoughts. First-person narratives by siblings would go a long way toward helping professionals to better understand the experience of life in the family.

How do family members balance each other?

There was agreement among mothers, fathers, siblings, and the family as a whole that siblings who are handicapped are significantly more process oriented than siblings who are not handicapped, (mothers: $p = .002$; fathers: $p = .001$; siblings: $p = .042$; family: $p = .0001$). This has implications in terms of the balance of the family. The reality that the handicapped child will be able to contribute less to the tasks of the family system is one which must be addressed by each family member. However, rather than viewing that purely in terms of deficits, the contributions which the handicapped child makes in terms of process issues can also be seen. The handicapped child serves to pull the family toward process issues more than a similar child who is not handicapped, in another family. This can mean that the family has an impetus for dealing with emotions, in that there can often be a forum for discussing process which emerges naturally from the family, in a non-crisis mode.

There is a need for additional information, though, about how siblings in families with handicapped children view their own responsibility with regard to tasks, and to the role of the handicapped child with regard to the expression of emotions. Talking with siblings about this, both while they are in their families, and in retrospect, can provide a beginning for better understanding this dynamic.

III. Summary

The perspectives which siblings have are always unique: embedded issues of love, jealousy, protection, anger, and territoriality effect daily interactions in the family, and retrospective analysis of the family situation. The experience of a handicapped sibling brings a special kind of intensity, and responsibility to the generic experience of being a sibling. This paper has attempted to show the ways in which the experience of having a handicapped sibling is both common to and different from the experience of having a non-handicapped sibling. It is hoped that further research and documentation will further clarify this important topic.

BIBLIOGRAPHY

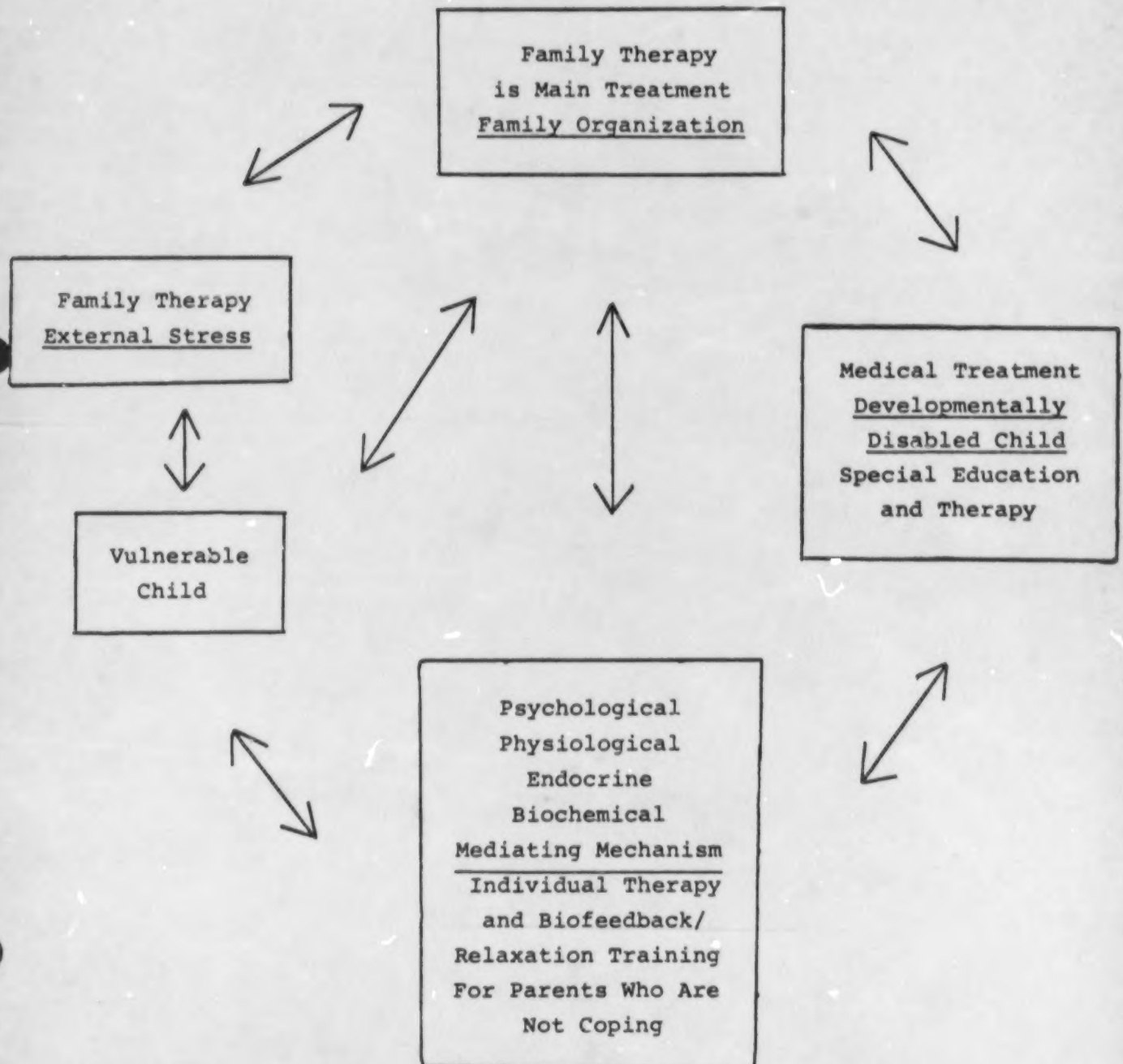
- Bales, Robert Freed. Personality and Interpersonal Behavior. New York: Holt, Rinehart and Winston, Inc., 1970.
- Bales, Robert Freed and Choppen, Stephen P. SYMLOG: A System for the Multiple Level Observation of Groups. New York: The Free Press, 1979.
- Bank, Stephen and Kahn, Michael D. The Sibling Bond. New York: Basic Books, Inc., Publishers, 1982.
- Barsch, Ray H. The Parent of the Handicapped Child: The Study of Child-Rearing Practices. Springfield, Illinois: Charles C. Thomas, Publisher, 1968; second printing, 1976.
- Farago, Sharon C. "A Study of the Relationship of Birth Order and Position in the Family Social Hierarchy in Families With and Without a Moderately Mentally Handicapped Child," unpublished Ph.D. dissertation, New York University, New York, New York, 1983.
- Farber, Bernard. "Family Organization and Crisis," Social Research Monographs on Child Development, 1960, 75, 1-94.
- Farber, Bernard; Jenne, William C.; and Toigo, R. "Family Crisis and the Decision to Institutionalize the Retarded Child," Council for Exceptional Children, NEA, Research Monograph Series, Series A, No. 1, 1960, 1-66.
- Farber, Bernard, and Ryckman, David B. "Effects of Severely Mentally Retarded Children on Family Relationships," Mental Retardation Abstracts, 1965, 2, 1-17.
- Featherstone, Helen. A Difference in the Family: Life with a Disabled Child. New York: Basic Books, Inc., Publishers, 1980.
- Freud, Sigmund, "Mourning and Melancholia," 1917, Standard Edition, XIV, London: Hogarth Press, 1956.
- Greenfield, Josh. A Place for Noah. New York: Holt, Rinehart and Wilson, 1978.
- Grossman, Frances Kaplan. Brothers and Sisters of Retarded Children: An Exploratory Study. Syracuse: Syracuse University Press, 1972.
- Rosenbaum, Milton, "Psychological Effects on the Child Raised by an Older Sibling," American Journal of Orthopsychiatry, April, 1963, 33, 5-17.

Solnit, Albert J. and Stark, Mary H. "Mourning and the Birth of the Defective Child," in Psychoanalytic Studies of the Child, New York: International Universities Press, 1961, 16, 523-537.

Sutton-Smith, Brian and Rosenberg, Bernard G., The Sibling. New York: Holt, Reinhart and Winston, Inc., 1970.

A Model for Organizing Intervention

Implications for Treatment



THE SIBLING CHILD: IDENTIFYING AND WORK WITH THE
SIBLINGS OF THE FAMILY WITH A DEVELOPMENTALLY DISABLED CHILD

- Leonard Silverstein

Abstract

Psychological care for the sibling child presents a crisis for the family. Families with effective organization do manage the child and the developmental delay, with minimal difficulty. However, poorly organized families may have difficulties. Six principal characteristics and guidelines for managing the siblings of these families are identified and discussed.

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The context for treating this type of family is in the view of the family as a unit except when psycho-physiological mechanisms become non-adaptive. Then biofeedback and relaxation techniques are used. The cerebral palsied child and a sibling usually cannot be treated outside of the context of the family and in that context we could see that poor family organization leads to additional problems in coping. Primary amongst these problems is (1) poor parental leadership. If you have a parent that doesn't exert any leadership in the treatment of the child; in obtaining services and is not an advocate for the child, then this passivity is a possible problem later on in dealing with the sibling.

If you are cognizant of (2) overt parental marital strife; if they come to the class yelling and screaming at each other; if they cannot agree on the treatment; if you make suggestions and they never follow through because they are too busy fighting with each other about what should be done; these are the characteristics of a family that has or will have problems with their sibling child.

Another factor is (3) serious external stresses which can be seen in the model for intervention (left hand corner of the drawing). An example is the loss of a job. If grandparents are part of the support system, and due to their advanced age, if they should die, this could create an external stressor and could be an additional pressure, but at other times it could help the non-CP child. Interestingly enough, sometimes what happens is that the two children get closer together because they have to support each other in the absence of one of the parents. Perhaps out of fear of being totally alone. So sometimes it could be positive stress to have the parents divorce each other.

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When a parent shares with you that there is a (4) discipline problem with all her children, family therapy is needed. In other words she says, "I really can't control Tommy the CP child, or Janie either. They are both running wild in my house and tearing down the shelves, and I can't discipline them." When we have those conditions, this is a characteristic of a family that is in need of psycho-social intervention.

The other thing is when the parents perceive that (5) mismanagement of the cerebral palsied child is justified because it is a very serious illness and they really can't handle him because he is that seriously impaired; in that case there is a potential problem that can best be dealt with by family therapy. (6) Poor control through overprotection is just as bad as poor control due to emotional distance of both parents in which they give up supervision of the child and they sort of "drop them off" at our center and they pick them up and they don't do anything afterwards because they are overwhelmed. If we see those kind of things, that is, parents are not really involved with their child. When you see that, then that's another possible stressor and family therapy is the focus of treatment.

Now, there are other characteristics in the family unit. There could be psychological problems. Very often parents of our children develop physiological symptoms because of this stress of caring for a cerebral palsied child and the other siblings. That could be manifested in a family of stress disorders, such as high blood pressure, headaches, cardiac arrhythmia and other physiological symptoms. When parents report these physiological symptoms, it could be due to the stress of everyday living with the additional stressor of the management of the illness; the round of medical appointments; the rounds of surgery. We have families in our center who for years have never gone on vacation because they can't leave their child with anyone. We hear all these kinds of conditions. They could lead to different health problems, in the family. The purpose of the respite program is to allow families to confront their problems of management and emotional fatigue of everyday living.

A typical kind of physiological disorders is asthma, which for many people is tension related. So these are the six characteristics of families whose siblings are at risk. Let me review them. Poor parental leadership; marked overt marital strife; serious external stresses. The fourth one is discipline problems with children. Fifth is justification of poor control due to management of illness, and emotional distance or overprotection of both parents, leading to inadequate supervision. This lack of supervision exacerbates the condition of the vulnerable non-cerebral palsied child.

All of these six factors can contribute to the disruption of the family organization, a variety of stress related

disorders which we treat here at the center including migraine and tension headaches. The psychological and psychophysiological mechanisms which underlie these stress disorders in parents are under study at our center in individual therapy (see model of intervention diagram).

These are six points for managing the family. I am going to discuss treating them. What I am saying in a general way here are some of the things that can be done. "Yes, there is help to overcome the problems." The focus of the treatment is the family. That's the focus of control for the management of any problem, and effective family organization allows you to make changes in the children: yes, it's possible, but you have to alter the way in which the family interacts, in order to make it reality. So how do we do that? The first step in the treatment is for the family to identify the problem and say, "Help."

Many times the father's role is constricted and one reason that there is poor family organization is that the father's role is that he should just work, and the mother undertakes all of the illness management. That leaves the father at an emotional distance, many times. It also leaves him not understanding the chronic state of illness, since he has to get the information from his wife, who may or may not be capable of sharing with him the understanding of what is going on in both the vulnerable child, the sibling, and the cerebral palsied child. If somebody is working two jobs, they end up at an emotional distance because there is no quality time for the family. One of the things that we find in families that have poor organization-they never sit down to dinner together-I mean never.

Mother is overwhelmed so comes the weekend she doesn't make dinner, and if you have a family that only has Sunday dinner together, it is a marginal family. This fact isn't in any textbook, this is my experience over the last ten years. If you have families where the father and the mother and the children sit down together each evening, they do better. Their organization is much better. It seems to me that this is a time in which they can communicate their hopes and their successes, they communicate their failures and they get feedback and information about how to cope with them from the parents and from each other. If you don't have this, and if you don't have any shared goals, it's usually a very marginal family and they don't do very well. Their organization is very poor. And this applies, whether you have a CP child or not. You can turn it around, you can say to the children, "Listen, you will be home at 4:00 p.m. or whenever you have dinner on Sunday and you have started at least one day a week. That's a minimum requirement. You should devise projects for the whole family to work on together. That's helpful. And we do that with siblings, we have projects where they make up little books and things to share with their brothers or sisters who are

handicapped. So we involve the siblings with their CP child. The same thing can be done for the family of so called normal children, of course.

The other thing is, when you have parents that are at a distance, what you try to do is involve them in a manner that I just described. This is guideline for management for family organization, not only sitting down to dinner, which sounds really routine, but is not.

Another possibility would be to put the parents in charge of managing the illness together as a team. Even though the children could be very young, the children learn to use the parents (one against the other), and some parents say, "I am overwhelmed," and they abdicate all parental responsibility. When there are no rules, there is "chaos." You can't have that. Children have to have guidelines, and you have to reinforce the parents, if you can get them to come in together, you can discuss how they should handle certain situations. A common thing when they get older might be, "What is the curfew?" Which means, what's the time you have to be home." How does a family manage going out to a party? What are the rules about drinking? Are there rules concerning sexuality?

Other issues may come up as the children get older. When they are little, there are different issues. For example, when one says to the child, "Why didn't you come in for dinner?" And she says, "Well I didn't hear you till you called me the third time." Parents sometimes get those kind of answers, and what this says is they are really hearing the question, but they don't understand the difference between "requests" and "demands." If everything is a request the child can say "no." The parent on the other hand, may be saying that everything is a demand, and the child has to obey immediately, and we try to work it out that somewhere in between is the reality.

One needs to negotiate "half a loaf," which many families do not do at all. One or the other parent makes demands disguised as requests and vice versa. So I tell stories and Jack and Jill who always resolve their problems by compromising and taking a half a loaf and eventually in that context they begin to negotiate their management of the illness, and it provides a context for problem resolution.

Working together or Building Family Cohesion!

Fathers should occasionally take off work and see the doctors and find out what's going on right from the horse's mouth. You know, it gives the fathers a greater sense of participation. This is an important characteristic for building cohesiveness. The other thing fathers should get involved with is high quality inter- actions with the siblings. This means that there would be organizing for trips that you and I may take as ordinary, but if you have somebody in a wheelchair, it may be difficult to do. Such as family

picnics, a day at the beach, whatever the family likes to do. It used to be in Nassau County, maybe they raised horses and they took care of horses, but we don't have that anymore.

In a more rural life, there are more chores and reasons for the family to hang together. Today, there are less reasons. Although you could wash the car together, I suppose. It could be anything, as long as it provides an opportunity for the family to be together. Now, when we were younger, they used to decorate the tree with popcorn. You know, now you buy ornaments in the store, you throw it on the tree, and it takes five minutes. You used to make your own decorations and the family used to have to get together to do this project. So those are the kinds of things that are needed. Sitting around the TV set does not qualify for high quality family interaction. You do find that during commercials they may interact a little because families who sit around the TV do better than families who don't ever get together. So in between commercials or incidents, or whatever there is some interaction. So if you watch TV together, that's better than not doing anything. But it is not as good as some other things such as going to the museum or whatever shared thing. Other examples might be taking pictures together, it could be almost anything. When things that are suggested by parents in therapy cost money, it is an excuse or a code word for "We really don't know how to get together and enjoy each other." "It costs too much." What they are really saying is they don't want to spend the emotional energy because of the arguments and fighting and so they push each other away.

Understanding the Immaturity of the CP Child

Another important point is that the parent has to learn to understand the immaturity and the level of development of the cerebral palsied child and not to keep comparing them to other children. Many times the CP child grows disrespectful because he/she is overprotected and indulged. The cerebral palsied person really has the problem that is disorganizing the family. And the nature of the problem is the child is not equipped in an early age to deal with the extent of their limitations. They still want to do everything and be like everybody, but there are some very real limitations that they have to confront. If they do not confront their limitations they become destructive and disrespectful to the parents. There are certain things you cannot do when you are in a wheelchair, and this is realistic. So we try to get the parent to understand the diagnosis and that the limitations are in everyday living. That's the role of the professional in this context. This means that when you ask the family to do a certain activity, to what extent can the child participate?

Parents Need to Work Together

The fourth thing that we try to do in managing a cerebral palsied child and his siblings is to get the parents to work together. No matter how handicapped the kids are, they seem to

read faces and nonverbal language very well, and they always manage to offset one parent against the other. And it may be that one parent is overprotective and the other is at an emotional distance. So we would usually have devisiveness that leads to problems with the sibling. This creates a stress on a family that leads to the non-cerebral palsied child becoming very willful and acting out in many ways. In the center (UCP), however, I don't know the reason, I mainly see young boys, I don't know what happens to the young girls. I guess they go somewhere else when they have a problem. I think there are other agencies that care for the young girls. For example, if they get pregnant, they wouldn't come here, (UCP) they would go to other agencies that handle out of wedlock mothers. There are different ways of acting out and we usually don't see young girls here. What we do see is the vulnerable child who is aggressive and acting out. That is, if he is punching people, if he acts up in school or gets in trouble with the teacher or throws a chair, or if he has low marks or bad school adjustment, then we might treat them. Otherwise we don't see them as patients.

Usually we treat them in the context that requires at least one parent to come in and learn how to manage the child. The sibling will use the grades to get back at the parents and to show their anger at how things are going in the family. So what we do is try to get the parents to back off and to give the message that the child's grades are their own and the parent cannot live through the child's grades. Children have to make a choice for themselves and in the final analysis they are the ones that have to get the grades, not the parents. This is sometimes a difficult idea to get across.

The other thing that we try to do within the context of the family is support cooperation among siblings. And the interesting thing is that as I mentioned earlier many times divorce in the family will increase the cooperation of the siblings and it has always been a surprise to me. In other words if you have a bad relationship, sometimes it's better for the children if you let the bad relationship go because they pull together more and they accept more responsibilities. Let me put it more concretely. Many times a mother goes shopping, brings the food home and she says, "Now help me unload the supermarket order and put it into the cabinets." And Jonnie says, "I've got a date with Janie, I'm leaving now, I've had this date for two months. I'm going out." And Jimmie says, "Something I've got to do in the basement," and he disappears. And then the father says, "I'm reading a book," and he goes upstairs and then mother is alone in the kitchen. If the family got together, they could do it all in fifteen minutes. It takes the mother an hour to unload the station wagon and put everything away. So now mother says, "This is a bunch of nonsense," and she "bugs out," so you've got Dad and the two kids and a handicapped kid without a mother. Guess what, after he does the supermarket order which he never did, they are done

in ten minutes, so they are actually doing better. This is the kind of situation we need to discuss. Families feel they need two parents, but if they can get one, they take it and they work harder to hold on to that one parent. But before that happens we try to support the cooperation of the siblings and the parents in achieving common goals that every family has, spoken or unspoken.

Everything I have said so far could apply to a family without a handicapped child, couldn't it? So one of the major objectives of this family therapy is to increase the stability of the family unit. Because in our culture that is still the basic unit that provides most of the daily care. In that context, what we try to do is shift the concern away from the condition of the cerebral palsied child to the issues of normal family adaptation. By normal we mean issues such as Mom and Dad are fighting, "Gee, you children really shouldn't be that upset because you don't hear them make up later on because they close the door." These days a lot of families have the notion that as soon as the parents fight, there will be a divorce because there's lots of divorce today. If parents have a fight, or get upset, the children often say, "When are you two splitting up?" What we try to do is bring out these issues that all families have disputes; the only issue is how do you handle upsets. How do you process an upset in a family in a normal psychosocial way, and what you do is you talk about the upset. You say, "Hey, I think I've got a problem. How do we go about solving it?" One answer often is, "Make a time to sit down and discuss the problems of the week." And we find in the context of the family that when they try to problem solve they interrupt each other. If you interrupt somebody and don't let them finish, you are always so busy telling about what's bothering you that you don't listen to the other person, you can't process the upset.

The bottom line is the family has to take time to listen to each other. This is normal psychosocial adaptation. When one family member is the spouse or sister, or whatever are thinking "Now what am I going to say next," instead of listening. That brings us to the most common complaint that we get from these families. It is a lack of communication, so at UCP we work on this problem and we believe that communication can be taught. A problem solving approach should be taught in the context of the family. How to negotiate some of your requirements is important. This is really not a concern with cerebral palsy per se; rather, what we try to do is shift their attention to this process. Unfortunately, the handicapped often have many health problems. Surgery is required in many cases. There is a constant round of going to the doctors, but at some point, at some age, this round of doctor visiting decreases.

The family interest in health problems may diminish depending upon the health of the child so you have another opportunity to communicate what needs to be done next to

maximize benefits. Often I am asked, "How long could this be going on before you can effect a change"--it could be years, but it still is possible.

So once again the guidelines for management are, put the parents in charge of the illness management, involve them in high quality interaction with the siblings, understand the immaturity and disrespectfulness of the CP child and how it effects the normal child. Try to obtain parental agreement in management, and progress and growth may emerge with ease for all involved, the CP child, the siblings and the parents.

NEEDED RESEARCH THRUSTS CONCERNING AND INVOLVING SIBLINGS

- Meyer S. Schreiber

As one surveys research in the field of the family it is clear that there is still all too little inquiry regarding siblings. This state of affairs in the general area of family research contributes to the limited interest in research activities concerning normal siblings of mentally retarded and other developmentally disabled persons.

Whatever research has been undertaken in the field of developmental disabilities marks its inception with Farber's pioneering work, but ends abruptly in the late 1970s with the considerable diminution of federal funding for such activities in the country's colleges and universities. Consequently the trickle of research that evolves now comes from devoted and interested faculty members who stimulate their students to undertake such needed areas of inquiry.

Looking backward, most of the research undertaken focused upon the impact of the presence of a person with a handicapping condition (such as mental retardation), upon the structure, function and development of the family, including the normal sibling. Attention was paid to what could be considered family pathology, or abnormal features of family development. My own view is that some of this research did not fully attempt to understand what was truly pathological in terms of family functioning.

Some other research efforts have focused upon the impact of the normal sibling upon the brother or sister with the handicapping condition. This line of inquiry has not been developed more fully.

The total family and the interacting and reciprocal impact of family members upon each other, the workings of family subsystems and similarly, their interactions and impact, has not been really confronted in the research effort.

It seems to me that as one listens to and hears the siblings, parents and professionals who are present at this Seminar, and at similar events, considerable material for grounding and initiating needed questions dealing with the normal sibling in the family exists in considerable quantity and quality.

I see a number and variety of directions that are needed to help us understand family life; and more specifically, the sibling experience. These are:

1. Some longitudinal study over a period of years, dealing with how relationships are established and the nature of sibling and parent interactions; and the totality of the developmental sequences involved in the family.

The developmental and longitudinal studies need to be compared with those of families where there is no member present with a handicapping condition, to compare parent, sibling and other family influences as well as those outside of the family proper.

2. There is all too precious little material available from siblings' materials as they construct their world of social reality. Much of what we do has come from observations of professionals, and some parents. However, the unique and individual experiences of the sibling have not been tapped into. Here the insights and contributions from qualitative sociological approaches would add immeasurably to our understanding.
3. A variety of variables might be included in the longitudinal studies suggested or be dealt with separately. These include:
 - a. The differences or similarities in families where there is one normal sibling or more than one such sibling.
 - b. The differences in age of siblings; in age of parents.
 - c. The impact of socio-economic factors, including race and ethnicity.
 - d. Different parenting models.
 - e. Different family structures, such as the one parent family.

I believe that these three broad areas for possible inquiry regarding sibling and family life are a beginning in attempting to provide a more basic and fundamental approach to our research efforts which hopefully will lead to improved services as we share what we have learned with siblings and families.

I would like to particularly indicate my own bias or interest in the utilization of siblings themselves and the opportunities that such directions provide for grounded theory. I am currently interviewing adult siblings, and am finding a veritable rich source of materials here as siblings describe the perceptions and meanings they attach to their past

and current experiences. A number of directions are already indicated for research efforts as I have learned about what it means and feels like to be a sibling.

Finally, the lack of funding mechanisms for such needed research severely limits our thrusts and movements forward. It is hoped that new sources for such activity will be forthcoming and helpful to scholars who evince such interests in siblings.

REPORTS OF DISCUSSION GROUPS

A. Siblings - Bonnie Cohen, Reporter

As a microcosm of the larger sibling movement, the lunch-time meetings at the two day conference served to demonstrate the growing excitement, warmth and camaraderie that adult siblings have just recently begun to share with each other in an organized way. As participants met with other people from various parts of the country, it was evident that we all shared a similar life concern with one another and with our respective families. That is in some ways different from the normal, traditional families which we were shown on television. Although we are all very different and unique as a result of our own experiences, we recognize in one another an understanding and concern for the commonality regarding certain issues, feelings and needs that are our common experience.

It was evident that there continues to be a need for a forum for newly aware siblings to share, encourage and support the positive and negative experiences of other siblings. For some, this conference was the first opportunity to meet and talk with other siblings! Some individuals came to the conference as professionals, and at some point during the proceedings, became aware of their personal issues, and "came out" as siblings. They expressed joy, excitement, anxiety as well as anger at their newly discovered identity--an identity which is not always acknowledged.

Issues of identity, rage, guilt, responsibility and pride are for each of us at different stages of awareness, development and resolution. At some point in our development, we need to act on the premise that our own needs are of primary importance. In many of our families, we were not allowed or encouraged to do this, as our handicapped sibling received a lion's share of time, attention and financial resources. Often, it was the handicapped child's needs around which the family pivoted.

We have feelings of both partnership and mistrust toward service delivery agents. We appreciate what is done, and anguish over what is not. We need to learn to avail ourselves and our families of the services offered and we need to learn to make the system and individuals in the system responsive to the unmet needs of our handicapped siblings and of our families. Some of us are not yet ready to advocate for others, as we have not yet finished advocating for ourselves.

We need to effectively communicate with our parents the concerns we have for ourselves and our handicapped sibling without shame or guilt. We need to hear the honest concerns of our parents.

We have many common needs, however, for each of us a different need is the priority at this time. This may be developmentally or situationally determined. It may be an obvious generalization, however, one which nevertheless needs to be clearly articulated: Although we have concerns which we would like to be recognized and understood by others, as well as ourselves, we, as siblings want to be happy, well-adjusted adults who can responsibly manage the needs and responsibilities which our families present.

Fortunately, we have discovered the magic of mutual aid and support in our encounters during this conference and as a function of the interest in siblings which everyone here today shares. The future promises exciting things for siblings. We benefit from the lessons of the parent's movement.

B. Parents - Cory Moore, Reporter

Our parent group over the two days ranged from the mother of a six month old baby to the mother of a 40 year old man. One parent of two children with disabilities has a twin with Down's syndrome. One couple has an impressive adoptive family representing a number of handicapping conditions. Our experiences, spanning the decades, were sometimes similar, particularly in the area of how doctors first impart a diagnosis and prognosis.

There was in our group considerable agreement and some differences in outlook--possibly occasioned by where we are in our own lives. Most definitely what emerged in discussion bore implications for professionals and, more broadly, for society at large.

So, to my fellow professionals:

Parents spoke first to the need for services:

- Group homes.
- Respite care that did not involve the cooperative payback of caring for someone else's child.
- The need for one central clearinghouse for information (available in some areas of the country) to help families find all services; moving to new locations presents an almost insurmountable challenge for our adoptive family of nine.
- Parents want support groups -- other who understand and can help. But we are not interested in discussing the early pain forever.
- Parents want training programs for parents -- in advocacy, in how to handle behavioral problems, in how to communicate with professionals.
- Parents want sibling groups for their young children as well as for adolescents -- children need support and may not feel comfortable asking parents for it.
- Parents are angry about waiting lists. They understand all too well that money may make a significant difference in how our children will fare -- and yet isn't a test of society what it will do for those of its citizens most in need?
- More parents are angry about categorical placements and labels defining the child. We want more noninstitutionalized services, we want our children in generic

recreation, we want for all our children the community access expected by their brothers and sisters. To that end, we want to see attitude training for the community, school education programs. I personally would submit that the best learning comes from those interactive activities in community and school setting that are still all too infrequent in our separate but equal approach. Separate is inherently not equal. If we don't want to raise another generation of bigots who will perpetuate the problems currently faced by parents and siblings, we must work to have all our children seen and known and part of everybody's world. In my town, we're working on it by placing, over a three year period, ten small classes of severely and profoundly multiply handicapped students in seven different regular elementary and secondary schools where they interact with their nondisabled peers and participate daily in community-based programming. It's a wonderful and exciting project and it is making a difference for both sets of students, for faculty, and for families of parents and siblings.

- We see the changing needs as our children grow and transition to new programs after preschool or no programs in late adolescence and adulthood.
- We worry, endlessly, about our adult sons and daughters and the implications for their siblings - the lack of social opportunities, the mini-institutional qualities of some group homes with constant staff turnover for people least equipped to deal with change. Group home counselors need better training. We are outraged by schools and workshops that still insist on the developmental, from the-bottom-up, first step first, model rather than age-appropriate activities. If people with severe mental handicaps must learn to manipulate Fisher Price toys and stack blocks before they can use stores and shopping centers, learn numbers before they can be travel-trained, they will forever be consigned to sitting at tables with toys. More can be done; more is being done. Lou Brown and Marc Gold and Paul Wehman and Tom Bellamy have proved it.

Now, to my fellow parents:

For those of us who have walked the road the longest, we must be sensitive to the needs of our newest travellers. We who are survivors preach the significant and all-too-true doctrine that it's important to be "twice as tough," to take a leadership role in educating others. One young parent in the group quietly observed it was like telling her to be six feet tall. We parents must never forget those early days of our own pain and depression and desperation and self-absorption and constant physical work. It's all right for new parents to feel

frail and sad and overwhelmed and weak and incapable. We need to offer our support, our empathy, our courage, our strength; they will -- most of them -- get to where we are in their own time -- even if they don't believe it today.

And now to the siblings:

You who are adults, who have always recognized the moral responsibility for your brother or sister and who have taken or will take on his or her direct or indirect responsibility even when parents are consciously trying to spare you that burden -- Continue the quest for a new vision. So many of you are professionals. You are consciousness-raisers for your peers. You have the opportunity to help parents -- your own and others -- to face the future and plan ahead. You can help those younger, newer siblings who need role models unencumbered by anger toward parents who may not always have done it right but always did the best they were capable of doing. We cannot change that which happens to us or has happened in the past; we CAN change what we choose to do with that experience. Talk. Preach. Be honest. Educate others. Advocate; many of you do. Write articles. Write books for children that are from a real sibling's perspective. Let the world know your unique point of view. And please -- don't reject what those who did not walk in your shoes have to offer. Don't repeat the same mistakes some parents make in rejecting those good things professionals can provide.

What we all must do -- parents, siblings, professionals -- is listen to one another, acknowledge all our truths, try to understand, and work together for a better world for everyone.

C. Professionals - Meyer S. Schreiber, Reporter

Of all the three groups involved in The Seminar, the professionals represented the largest number of persons in attendance at this event. This fact can be viewed as a positive one, indicating that such individuals came to listen, to share and to learn not only from each other but from siblings and parents as well. In another way, this considerable representation reflects a common and perennial development; that wherever one goes to conferences dealing with families, individuals, siblings or parents, there are always more professionals in evidence than any other group.

The group present at this two day educational event was a heterogeneous one; the professionals presented came from backgrounds that included being a sibling as well; from voluntary, private, social and educational agencies; from public county and state programs; from work as psychologist, nurses, social workers, learning disability specialists, group home staff and a host of other professional activities. Some had little or no experience in work with siblings; others were quite sophisticated in terms of their backgrounds and work experiences.

Most of the time during the two luncheon discussions was devoted to a sharing of experiences and a probing of various professional interventions to learn how to more adequately deal with the needs and concerns of siblings. The most common concern was related to how to recruit siblings for services individual professionals and their agencies were ready to sponsor. Consequently, the give and take, the flow of the discussion, centered on how to identify siblings, how to interest them in being involved with a human services organization. There was considerable discussion dealing with the understandings and insights needed to work with different age groups.

The thirst for knowledge, for opportunities, for skill development, on the part of those who came to The Seminar was genuine and impressive. However, sometimes it appeared like some individuals wanted instant answers and instant solutions as they were so concerned with the centrality of their helping roles. It seems to me that all of us need to take a critical and careful stance in applying the finding of professionals from one setting to another.

The outstanding feature of these two luncheon discussions was the desire to learn more about siblings and their worlds, and to be and to become more competent in addressing such vital human concerns.